BMJ Open

# The impact of covid-19 restrictions on behavioural and psychological symptoms in home-dwelling people with dementia: a prospective cohort study (PAN.DEM)



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| Journal: | *BMJ Open* |
| Manuscript ID | bmjopen-2021-050628 |
| Article Type: | Original research |
| Date Submitted by the Author: | 25-Feb-2021 |
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| Keywords: | Dementia < NEUROLOGY, COVID-19, Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Old age psychiatry < PSYCHIATRY, PRIMARY CARE |
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# The impact of covid-19 restrictions on behavioural and psychological symptoms in home-dwelling people with dementia: a prospective cohort study (PAN.DEM)

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Word count: 2463

## ABSTRACT

**Objectives**: To investigate the impact of the covid-19 restrictions on behavioural and psychological symptoms of dementia (BPSD).

**Design**: Prospective cohort study (PAN.DEM) nested within the halted parent study (LIVE@Home.Path).

**Setting**: Households in municipalities in Norway immediate before and six to nine weeks into the covid-19 restrictions.

**Participants**: 104 dyads (persons with mild to moderate dementia aged ≥65 and their informal carers) completed both pre- and pandemic assessments amongst 237 in the parent study. Mini-Mental Status Examination (MMSE) score 15-26 or Functional Assessment Scaling (FAST) score 3-7 covered dementia severity.

**Main outcome measures**: Neuropsychiatric Inventory (NPI) psychosis, hyperactive behaviour, mood, and total score; Cornell Scale for Depression in Dementia (CSDD) total score.

**Results**: Psychosis increased during the covid-19 restrictions compared with pre-pandemic averages (from 2.38 to 3.89, P=0.01). Psychosis worsened in 37(36%) persons; ten-fold with partial insight (logistic regression, odds ratio 9.57, 95% confidence interval 1.14 to 80.71) and four-fold with reduced carer contact (4.45, 1.01 to 19.71), in addition to impaired function by FAST (2.59, 1.07 to 6.27) and dependency (0.68, 0.51 to 0.91). Moreover, depressive symptoms increased by CSDD total score (6.33 to 7.64, P=0.02) and worsened for 56(54%), also associated with impaired function (4.96, 1.57 to 15.65), Alzheimer's dementia (0.21, 0.05 to 0.85), and psychotropic drugs on-demand (0.16, 0.03 to 0.75). Regarding NPI, the numbers of BPSD with symptom load of clinical relevance increased (from 2.29 to 3.12, P<0.001), while total score did not change significantly (from 18.36 to 21.55, P=0.06).

**Conclusions**: The levels of psychosis and depression increased, in addition to an increase in the numbers of BPSD with symptom load of clinical relevance during the first two months of the covid-19 restrictions. These BPSD exacerbations have implications for pandemic policies globally, emphasising that restrictions must balance covid-19 morbidity and mortality against dementia deterioration.

**Registration**: ClinicalTrials.gov; NCT04043364.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- This is the first prospective cohort study investigating the impact of the covid-19 restrictions on behavioural and psychological symptoms of dementia (BPSD).
- The same carers reported BPSD for each home-dwelling person with dementia both before and during the pandemic scenario using validated, well-established instruments.
- The covid-19 restrictions left some of the raters with less basis of observation.
- Our study captures the impact of the initial phase of the outbreak in Norway and does not describe the long-term impact of the covid-19 restrictions on BPSD.

## INTRODUCTION

Dementia is among the most critical risk factors for covid-19 mortality.[1] In England and Wales alone, 12,869 people with dementia have died, accounting for 26% of the covid-19 death toll.[2] Until vaccination is widely available globally, hygiene and physical distancing interventions have been and will remain cornerstones of protecting vulnerable populations.[3] The subsequent restrictions have been disruptive for home-dwelling people with dementia as private homes were not accessible to family members and volunteers, day care centres closed, and home nursing services were restricted to those most in need. As a result, people with dementia living in the community are not only at risk from covid-19 morbidity and mortality; they are also threatened from unforeseen effects of the restrictions.[4, 5]

Behavioural and psychological symptoms of dementia (BPSD) cover a wide range of clinical presentation including depression, anxiety, agitation, and psychosis. Longitudinally, persistent BPSD may be found in up to 80% of people with dementia.[6] BPSD are best managed with structured, non-pharmacological interventions, placing psychotropic drugs as secondary treatment options.[7] Preliminary evidences indicate that BPSD may be exacerbated under the covid-19 restrictions. In one study, informal carers reported worsening of anxiety, insomnia, and depression among persons with dementia eight weeks into the Argentinian covid-19 quarantine (N=119).[8] Another study identified worsening BPSD in 60% of a an Italian sample of dementia outpatients one month into the pandemic (N=4,913).[9] This study also found that 28% required changes in psychotropic medication to address irritability, apathy, agitation, and depression. Further, nursing home patients with dementia reported increased anxiety and depression when asked to evaluate their own experience of the pandemic retrospectively (N=58).[10]

However, all these studies are cross-sectional and thus far, there is a dearth of longitudinal data tracking changes in BPSD during covid-19 by comparing pre-pandemic to pandemic rates.[11] In this study, we aim to address this significant gap in the literature using data from

the prospective PAN.DEM study.[12] This study is nested within the ongoing LIVE@Home.Path trial[13] and was launched by our team to investigate the impact of the covid-19 restrictions (implemented in Norway on 12 March 2020) on home-dwelling people with dementia. Here we present comparisons of pre-pandemic and pandemic BPSD, and explore factors associated with worsening BPSD.

## METHODS

The parent study, LIVE@Home.Path, is a stepped-wedge randomised controlled trial.[13] It compares the cost-effectiveness in resource utilisation of a six-month multicomponent intervention comprising Learning, Innovation, Volunteers, and Empowerment (LIVE) to usual conditions for dyads of home-dwelling people with dementia and their informal carers. Dyads were eligible for inclusion if the persons with dementia were: ≥65 years, diagnosed with dementia (with Mini-Mental Status Examination (MMSE) score 15-26 or Functional Assessment Scaling (FAST) score 3-7)[14, 15]; home-dwelling in one of three Norwegian municipalities; and had weekly face-to-face contact with the carer. Trained data collectors blindly assessed all dyads in direct conversation every six months for two years (2019 to 2021). The pre-pandemic six-month assessment was close to complete when the covid-19 restrictions replaced trial protocol (figure 1, panel a). In response, we developed the semi-structured PANdemic in DEMentia (PAN.DEM) telephone interview for carers to capture if, and how, dyads were affected by the outbreak (supplementary file). This assessment included selected instruments from the parent trial in addition to questions regarding the pandemic. Between week six and week nine after restrictions were imposed (20 Apr. to 15 May 2020), we invited as many dyads as possible from the parent study to complete the PAN.DEM assessment. Potential respondents were considered unreachable when no response was given to two calls and a text message.

This study compares the pre-pandemic assessment of the parent study to the PAN.DEM assessment (figure 1, panel b).

*Figure 1 here*

### Assessments

The primary outcome was change in BPSD between the pre-pandemic and pandemic assessments. We administered two carer-rated scales at both time points. 1) The Neuropsychiatric Inventory (NPI) assesses frequency and severity of delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibitions, irritability, aberrant motorial behaviour, sleep disturbances, and appetite changes over the four preceding weeks.[16] Each of these twelve domains is scored from 0 (no symptoms) to 12 (very severe symptoms), a score ≥4 is regarded a BPSD with symptom load of clinical

relevance. These domains are further aggregated to generate subsyndrome scores for psychosis comprised of delusions and hallucinations (0-24), hyperactive behaviour comprised of agitation, euphoria, irritation, disinhibition, aberrant motor behaviour (0-60), mood comprised of depression, apathy, sleep disturbances, and appetite changes (0-48), and finally, a total NPI score (0-144).[17] 2) The Cornell Scale for Depression in Dementia (CSDD) assesses nineteen items of depressive symptoms during the prior week, each rated from 'absent' to 'severe' (0-2), or 'symptoms not possible to evaluate' (missing).[18] Adding item scores generate the CSDD total score (0-38).[18] The Norwegian versions of NPI and CSDD have robust psychometric properties.[16, 18-20]

In addition to BPSD, we collected the following data at the pre-pandemic assessment: the persons with dementia's level of functioning in activities of daily living by Physical Self-Maintenance Scale (PSMS)[21] and Instrumental Activities of Daily Living Scale (IADL),[22] health by the General Medical Health Rating Scale (GMHR),[23] possible dementia aetiology following the International Classification of Diseases – 10$^{th}$ version (ICD-10),[24] and use of health care services and medications as specified by the dyads. Drugs catalogued in the Anatomical Therapeutic Chemical Index (ATC) administered in a set schedule were regarded 'regular', whereas all others were documented as 'on demand'.[25] Psychotropic drugs included antipsychotic (N05A), anxiolytic (N05B), hypnotic and sedative (N05C), antidepressant (N06A), and anti-dementia drugs (N06D) by ATC. Demographical data (age, gender, residency, kinship) were self-reported. We evaluated dementia severity in terms of cognition with MMSE and level of functioning with FAST at inclusion.[14, 15]

At the pandemic assessment, the carers were also asked to estimate the degree of insight presented by the person with dementia into the covid-19 situation and change in 1) contact with the carer, 2) volunteering services, and 3) municipal health care services (home nursing services, home help, day-care, and in-home and out-of-home respite care) due to the covid-19 restrictions.[12] Finally, carers stated if contacts with health care professionals were postponed or averted.

**Statistical analysis**

After an initial aggregation of means (standard deviation, SD), and calculation of NPI subsyndrome scores and total scores for NPI and CSDD if >80% of the scales were answered, we used two-tailed paired t-test to assess change between the pre- and pandemic assessments. Next, we utilized multiple logistic regression analysis to explore factors associated with worsening NPI and CSDD sum scores. We included the following explanatory variables for persons with dementia: age, gender, residency, dementia aetiology, MMSE, FAST, IADL, PSMS, GMRH, number of psychotropic drugs prescribed regularly and

on-demand, the covid-19 specific outcomes. We also included age and gender of the carers. Missing data were handled with listwise deletion, with 14% missing any explanatory variables. The Akaike information criterion guided the model selection. Selected models were checked for multicollinearity, robustness, and goodness-of-fit by Pearson and Hosmer-Lemeshow test. Calculations are expressed in Odds Ratio (OR) with 95% confidence intervals (95%CI), and P value. Reported P values are two-tailed, and $P<0.05$ was considered statistically significant. We used Stata/IC, release 16 (StataCorp LP, College Station, TX) for all analyses.

**Ethics**

Dyads gave informed spoken and written consent for participation in the parent study as described in the protocol.[13] Carers gave additional informed consent to PAN.DEM.[12] The Regional Committee for Medical and Health Research Ethics approved the parent trial (2019/385) and PAN.DEM (10861) before data was collected.

**Public and Patient Involvement**

The conceptualisation, design, assessments, and conduct of the parent study as well as PAN.DEM included close patient/carer and public involvement.[12, 13] A user-representative participated in the research group's weekly meetings. In PAN.DEM, he consulted with the study team on priorities, length, and wording of the interview, and its revisions, with a special focus on the potential burden on carers.[12]

**RESULTS**

Of the 280 dyads participating in the parent study, 237 completed the pre-pandemic assessment from Dec. 2019 to Mar. 2020 (figure 1, panel b). This study includes 104 dyads recruited to PAN.DEM completing the pre-pandemic assessment before the covid-19 restrictions were effectuated 12 Mar. 2020. Mean time between assessments was 86 days (SD 19).

Table 1 shows that the mean age for people with dementia was 82 years (SD 7), 61% were women, 44% lived alone, and 50% received daily home-nursing services prior to the covid-19 restrictions. Alzheimer's disease constituted the most common dementia aetiology, while 6% had vascular dementia and 10% reported Lewy-body dementia or Parkinson's disease. Most people with dementia lacked insight into the covid-19 situation (table 2). The carers reported to have less contact with the person with dementia in 28% under the restrictions.

Table 1: Pre-pandemic characteristics for the 104 dyads (persons with dementia and informal carers, n).

| | n (%) | mean (SD) |
|---|---|---|
| *Person with dementia* | | |
| Age | | 82 (7) |
| Gender, Female | 63 (61) | |
| Residency | | |
| Living alone | 46 (44) | |
| Co-residing with the reporting carer | 46 (44) | |
| Co-residing with someone else than the carer | 12 (12) | |
| Dementia aetiology | | |
| Alzheimer's Disease | 45 (43) | |
| Vascular Dementia | 6 (6) | |
| Dementia in other diseases classified elsewhere | 10 (10) | |
| Unspecified Dementia | 43 (41) | |
| MMSE score, range 0-30 | | 21 (3.8) |
| FAST score, range 1-7 | | 4 (0.8) |
| GMHR, range 1-4 | | 3 (0.7) |
| PSMS, range 6-30 | | 12 (3.6) |
| IADL, range 8-31 | | 22 (5.1) |
| Drugs in general | | |
| Total number | | 6.2 (3.5) |
| Regularly | | 5.2 (2.8) |
| Psychotropic drugs | | |
| Total number | | 1.0 (0.9) |
| Regularly | | 0.9 (0.8) |
| Antipsychotic drugs (N05A) | 6 (6) | |
| Anxiolytic drugs (N05B) | 3 (3) | |
| Hypnotic/sedative drugs (N05C) | 10 (10) | |
| Antidepressant drugs (N06A) | 19 (18) | |
| Anti-dementia drugs (N06D). | 52 (50) | |
| On-demand | | 0.2 (0.4) |
| Antipsychotic drugs (N05A) | 0 (0) | |
| Anxiolytic drugs (N05B) | 5 (5) | |
| Hypnotic/sedative drugs (N05C) | 12 (12) | |
| Antidepressant drugs (N06A) | 0 (0) | |
| Anti-dementia drugs (N06D). | 0 (0) | |
| Health care services | | |
| Daily Home Nursing | 52 (50) | |
| Weekly Day Care | 29 (28) | |

| | | |
|---|---|---|
| Respite Care (In-Home and Out-of-Home) | 2 (2) | |
| Volunteering services | 8 (8) | |
| *Carer* | | |
| Age | | 65 (12) |
| Gender, Female | 68 (65) | |
| Kinship to the person with dementia | | |
| Spouse | 44 (42) | |
| Children | 58 (56) | |
| Others | 2 (2) | |

Table 1 legend:
Pre-pandemic: Six-month assessment of parent study (12 Dec. 2019 to 11 Mar. 2020). SD: standard deviation. ICD-10: International Statistical Classification of Diseases and Related Health Problems. MMSE: Mini-Mental Status Examination, at inclusion. FAST, Functional Assessment Scaling, at inclusion. GMHR: General Medical Health Rating Scale. PSMS: Physical Self-Maintenance Scale. IADL: Instrumental Activities of Daily Living Scale. Drugs were classified by the Anatomical Therapeutic Chemical Index; antipsychotics, anxiolytics, hypnotics/sedatives, antidepressants, and anti-dementia drugs constituted psychotropic drugs.

Table 2: Pandemic characteristics for the 104 persons with dementia (n) as perceived by their carers.

| | n (%) |
|---|---|
| Degree of insight | |
| Sufficient | 34 (33) |
| Partial | 54 (52) |
| To no degree | 16 (15) |
| Change in contact with the carer | |
| Reduced | 29 (28) |
| No change | 49 (47) |
| Increased | 23 (22) |
| Ceased volunteering services | 8 (8) |
| Change in health care services | 42 (40) |
| Postponed or averted contacts with health care professionals | 32 (31) |

Table 2 legend:
Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). Health care services provided by the municipality: home nursing services, home help, day-care, and respite care (In-Home and Out-of-Home).

From the pre- to the pandemic assessment, people with dementia experienced an increase in numbers of BPSD with symptom load of clinical relevance (2.29 to 3.12, P<0.001) (table 3). While the total NPI score did not change significantly (18.36 to 21.55, P=0.06), we noted increases in the NPI psychosis subsyndrome (2.38 to 3.89, P=0.01), with 36% experiencing more severe psychosis (figure 2). We also noted an increase in depression measured both by the NPI depression domain (1.96 to 2.73, P=0.04) and CSDD total score (6.33 to 7.64, P=0.02, table 3). The increase in CSDD was driven by the items 'multiple physical complaints' (0.39 to 0.59, P=0.02) and 'loss of interest' (0.44 to 0.65, P=0.04) (supplementary table A). Additionally, the CSDD total score worsened for 54% (figure 2).

Table 3: Pre-pandemic compared to pandemic behavioural and psychological symptoms (BPSD) for the 104 persons with dementia (n).

| | Pre-pandemic | | Pandemic | | |
|---|---|---|---|---|---|
| | mean | SD | mean | SD | P |
| *Neuropsychiatric inventory (NPI)* | | | | | |
| Total score, range 0-144 | 18.36 | 16.09 | 21.55 | 16.78 | 0.06 |
| Subsyndromes | | | | | |
| Psychosis, range 0-24 | 2.38 | 4.22 | 3.89 | 5.77 | 0.01* |
| Hyperactive behaviour, range 0-60 | 6.81 | 7.54 | 6.86 | 7.59 | 0.95 |
| Mood, range 0-48 | 7.63 | 8.56 | 8.53 | 8.53 | 0.35 |
| Domain scores, range 0-12 | | | | | |
| Delusions | 1.63 | 2.93 | 2.71 | 4.06 | 0.01* |
| Hallucinations | 0.75 | 2.18 | 1.22 | 2.82 | 0.06 |
| Agitation | 1.52 | 2.44 | 1.43 | 2.69 | 0.58 |
| Depression | 1.96 | 3.26 | 2.73 | 3.28 | 0.04* |
| Anxiety | 1.55 | 3.00 | 2.27 | 3.59 | 0.06 |
| Euphoria | 0.67 | 2.21 | 0.40 | 1.52 | 0.29 |
| Apathy | 2.42 | 3.52 | 2.48 | 3.71 | 0.84 |
| Disinhibitions | 0.76 | 2.13 | 1.23 | 2.49 | 0.09 |
| Irritability | 2.10 | 3.13 | 2.00 | 2.97 | 0.76 |
| Aberrant motor behaviour | 1.83 | 3.58 | 1.80 | 3.10 | 0.98 |
| Sleep disturbances | 1.97 | 3.43 | 1.92 | 3.34 | 0.94 |
| Appetite changes | 1.35 | 2.96 | 1.42 | 3.03 | 0.86 |
| Number of BPSD with symptom load of clinical relevance (NPI domain score ≥4), range 0-12 | 2.29 | 2.06 | 3.12 | 2.43 | <0.001* |

| | | | | | |
|---|---|---|---|---|---|
| *Cornell Scale for Depression in Dementia* | | | | | |
| Total score, range 0-38 | 6.33 | 5.26 | 7.64 | 5.02 | 0.02* |

Table 3 legend:
Pre-pandemic: Six-month assessment of parent study (12 Dec. 2019 to 11 Mar. 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). SD: standard deviation. P: P value for difference between time points by the paired t-test, * indicates two-tailed P <0.05. NPI subsyndromes: psychosis (delusions and hallucinations), hyperactive behaviour (agitation, euphoria, irritation, disinhibition, aberrant motor behaviour), mood (depression, apathy, sleep disturbances, and appetite changes).

*Figure 2 here*

Table 4 shows the results of the logistic regression models exploring factors associated with worsening BPSD under the restrictions. Worsening psychosis was associated with partial insight into the covid-19 situation (OR 9.57, 95%CI 1.14 to 80.71), reduced contact with the carer (OR 4.45, 95%CI 1.01 to 19.71), dependency in activities of daily living estimated by PSMS (OR 0.68, 95%CI 0.51 to 0.91), and impaired function as indicated by FAST (OR 2.59, 95%CI 1.07 to 6.27). Impaired function by FAST was also associated with worsening depressive symptoms (OR 4.96, 95%CI 1.57 to 15.65), contrary to Alzheimer's dementia (relative to other dementia aetiology, OR 0.21, 95%CI 0.05 to 0.85), and psychotropic drug use on-demand (OR 0.16, 95%CI 0.03 to 0.75) showing inverse associations.

Table 4: Factors associated with worsening in behavioural and psychological symptoms of dementia from the pre-pandemic to the pandemic assessment.

| Explanatory variables | Psychosis subsyndrome | | | | Depressive symptoms | | | |
|---|---|---|---|---|---|---|---|---|
| | OR | 95% CI lower | 95% CI upper | P | OR | 95% CI lower | 95% CI upper | P |
| *Pre-pandemic characteristics* | | | | | | | | |
| *Person with dementia* | | | | | | | | |
| Age | 0.91 | 0.82 | 1.01 | 0.16 | 1.09 | 0.97 | 1.22 | 0.16 |
| Female | 0.36 | 0.09 | 1.52 | 0.09 | 0.19 | 0.03 | 1.31 | 0.09 |
| Live alone | 2.69 | 0.41 | 17.80 | 0.31 | 0.55 | 0.07 | 4.18 | 0.57 |
| Alzheimer's Disease [a] | 0.84 | 0.23 | 3.08 | 0.79 | 0.21 | 0.05 | 0.85 | 0.03* |
| MMSE score [b] | 0.97 | 0.82 | 1.14 | 0.68 | 0.96 | 0.80 | 1.15 | 0.65 |
| FAST score [c] | 2.59 | 1.07 | 6.27 | 0.04* | 4.96 | 1.57 | 15.65 | 0.01* |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| IADL [d] | 1.19 | 0.98 | 1.45 | 0.08 | 0.84 | 0.67 | 1.07 | 0.16 |
| PSMS [e] | 0.68 | 0.51 | 0.91 | 0.01* | 0.99 | 0.76 | 1.29 | 0.96 |
| GMHR [f] | 2.06 | 0.72 | 5.88 | 0.18 | 0.84 | 0.28 | 2.50 | 0.76 |
| Psychotropic drugs [g] | | | | | | | | |
| Regularly | 0.67 | 0.31 | 1.47 | 0.32 | 1.11 | 0.49 | 2.53 | 0.80 |
| On-demand | 2.95 | 0.69 | 12.66 | 0.15 | 0.16 | 0.03 | 0.75 | 0.02* |
| *Carer* | | | | | | | | |
| Age | 1.04 | 0.98 | 1.12 | 0.21 | 0.99 | 0.93 | 1.06 | 0.87 |
| Female | 0.70 | 0.18 | 2.80 | 0.62 | 0.82 | 0.16 | 4.27 | 0.82 |
| *Pandemic characteristics, person with dementia* | | | | | | | | |
| Insight to the covid-19 situation [h] | | | | | | | | |
| Partial | 9.57 | 1.14 | 80.71 | 0.04* | 0.67 | 0.10 | 4.44 | 0.68 |
| Sufficient | 3.69 | 0.33 | 40.93 | 0.29 | 2.70 | 0.26 | 28.27 | 0.41 |
| Contact with the carer [i] | | | | | | | | |
| Reduced | 4.45 | 1.01 | 19.71 | 0.049* | 1.40 | 0.27 | 7.27 | 0.69 |
| Increased | 3.21 | 0.71 | 14.55 | 0.13 | 0.30 | 0.07 | 1.23 | 0.10 |
| Ceased volunteering services | 0.20 | 0.02 | 2.11 | 0.18 | 0.59 | 0.04 | 7.91 | 0.69 |
| Change in health care services | 0.48 | 0.11 | 2.08 | 0.33 | 1.16 | 0.28 | 4.83 | 0.84 |
| Postponed or averted contacts with health care professionals | 1.55 | 0.45 | 5.42 | 0.49 | 3.37 | 0.70 | 16.08 | 0.13 |

Table 4 legend:

n: 89 dyads (persons with dementia and carer). Pre-pandemic: Six-month assessment of parent study (12 Dec. 2019 to 11 Mar. 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). Psychosis subsyndrome constituting delusions and hallucinations by the Neuropsychiatric Inventory. Depressive symptoms by Cornell Scale of Depression in Dementia. OR: Odds Ratio, explored by multiple logistic regression, estimates adjusted for all other factors in the model. 95%CI: 95% Confidence Interval. *P*: two-tailed, * indicates *P* value <0.05.

[a]: Alzheimer's disease, reference: all other dementia aetiologies.

[b]: MMSE, Mini-Mental Status Examination, at inclusion, range 0-30, higher scores indicate better cognition, reference: 30

[c]: FAST, Functional Assessment Scaling, at inclusion, range 1-7, lower scores indicate better functioning, reference: 1

[d]: IADL, Instrumental Activities of Daily Living Scale, range 8-31, lower scores indicate better functioning, reference: 8

[e]: PSMS, Physical Self-Maintenance Scale, range 6-30, lower scores indicate better functioning, reference 6.

[f]: GMHR, General Medical Health Rating Scale, range 1-4, lower score indicate higher comorbidity burden, reference 4.

[g]: Number of psychotropic drugs according to the Anatomical Therapeutic Chemical Index: antipsychotics (N05A), anxiolytics (N05B), hypnotics/sedatives (N05C), antidepressants (N06A), and anti-dementia drugs (N06D), reference: 0.

[h]: Degree of insight into the covid-19 situation as perceived by the carer, reference: no insight.

[i]: Change in contact with the carer, reference: no change.

Post-hoc analysis did not show any association between use of antipsychotic drugs before the restrictions and worsening psychosis subsyndrome using unequal variances t-test (supplementary table B). Similarly, we found no association between use of antidepressants and worsening depressive symptoms. Neither randomisation to the intervention vs. control of the parent study was associated with worsening psychosis subsyndrome nor depressive symptoms (supplementary table B).

## DISCUSSION

Our primary aim was to compare pre- and pandemic levels of BPSD in home-dwelling people with dementia. We found an increase in the levels of psychosis and depression, in addition to an increase in numbers of BPSD with symptom load of clinical relevance, during the first two months of covid-19 restrictions in Norway. We further found that the odds for worsening psychotic symptoms increased ten-fold with partial insight into the covid-19 situation and four-fold with reduced contact with carers, while as-needed use of psychotropic drugs was associated with fewer depressive symptoms.

### Strengths and weaknesses

Our study provides prospective data obtained shortly before and under the covid-19 restrictions rated by the same carer for each subject and based on extensive assessor-blinded interviews with validated, well-established instruments.[12, 13] Our population was recruited to be representative to the Norwegian demographic in terms of dementia aetiology, stadium, and symptomatology.[13]

There are weaknesses to address. Despite efforts, we were not able to contact all potential respondents before the restrictions were eased for the first time, explaining the small sample size. In 28% of dyads the carer reported reduced contact with the person with dementia due to the pandemic, leaving some carers with less basis of observation. Despite the robust

psychometric properties of NPI and CSDD,[16, 18] these instruments are not validated for telephone interviews. Additionally, stressed carers might have exacerbated BPSD or communicated their own complaints during the outbreak, possibly leading to an overestimation of symptoms. Notably, our data capture the impact of the initial phase of the outbreak in Norway and can therefore not answer longer-term consequences from either reimposition or lengthening of invasive restrictions.

**Comparison with other studies**

This study provides initial data to demonstrate the negative mental health consequences of the covid-19 restrictions for people with dementia. Our findings echo a small body of the existing literature on this topic. A small study from Spain noted increases in levels of agitation, apathy, and aberrant motor behaviour five weeks into lockdown in outpatients with mild cognitive impairment and Alzheimer's disease (N=40), but no increase in psychotic symptoms.[26] A cross-sectional study from Italy (N=139) describes exacerbation of psychotic symptoms in a small percentage of subjects with subjective cognitive decline, mild cognitive impairment, and dementia.[27] This study, in part, utilised self-assessments, that may have led to underreporting of delusions and hallucinations. Other studies are equivocal on whether psychosis worsens,[8, 9] but UK registry data indicate substantially higher antipsychotic prescription rates to people with dementia during the pandemic, and the authors speculate that this increase may be the result of worsened agitation and psychosis.[28] Because this is a nascent area of research, discrepancies may be attributed to heterogeneity in design, as well as dementia stadium and aetiology.

Early findings suggest that older adults at group level are more resilient to the mental health effects of the pandemic than younger ones.[11] Nonetheless, our study adds to the cross-sectional reports calling attention to deteriorating depressive symptoms among people with dementia.[8-10] Anxiolytics and hypnotics/sedatives were used on-demand in our sample. These are drugs that are known to mask some of the symptoms assessed by the CSDD, which might explain why they appear preventive of depressive deterioration.

Our study confirms the World Health Organisation's concerns that the pandemic would negatively impact the mental health of people with cognitive impairments.[5] BPSD worsening, in parallel with distortions in daily routines from the covid-19 policies, demonstrate how vulnerable these people are to minimal changes within the immediate living environment.[7] Our finding that poor insight into the pandemic was associated with worsening psychosis, in particular, highlights the importance of clear communication with carers and health care services. Even though way of life varies globally, the policies implemented in response to covid-19 are likely equally disruptive to the environment of

home-dwelling people with dementia across nations.[3] We, therefore, argue that our findings are generalisable to other countries. Furthermore, they emphasise that nonpharmacological approaches still should be the first-line treatment to avoid BPSD deterioration.

### Unanswered questions and future research

Future research should explore the long-term impact of the covid-19 restrictions on BPSD, and whether moderations or interventions can mitigate worsening. Less than 5% of trials on covid-19 involve behavioural and mental health interventions,[29] emphasising the need for knowledge to adapt restrictions and navigate the unforeseeable consequences of the current, and future, pandemics.

## STATEMENTS

### Contributor and guarantor information

BSH was primary investigator. MHG, BSH, MV, and LIB designed and planned the study. MHG, MV, and LIB collected data. MHG did the data analysis, supervised by JM. MHG and LIB wrote the first draft of the manuscript. All authors were actively involved in interpreting the results, revising the manuscript, and approving the final version. LIB is responsible for the overall content as guarantor. The corresponding author attests that all listed authors meet the authorship criteria and that no others fulfilling authorship criteria are omitted.

Renira Angeles (postdoctoral fellow, NORCE) and Nathalie Puaschitz (postdoctoral fellow, Western Norway University of Applied Sciences) contributed to data collection. Rune Samdal secured public and patient involvement. The motivation and willingness of dyads and municipal personnel in Bergen, Bærum, and Kristiansand made this study possible.

### Transparency statement

LIB (the manuscripts guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study; that no important aspects of the study have been omitted; and that any discrepancies from the study as originally planned (and, if relevant, registered).

### Funding statement

This work was supported by the Research Council of Norway (grant number 273581). The Norwegian Government and the G.C. Rieber Foundation supports the Centre for Elderly and Nursing Home Medicine, University of Bergen, organising the conduction of LIVE@Home.Path and PAN.DEM. The research was designed, conducted, analysed, interpreted, and written by the authors independently of the funding sources. All authors had access to the data in the study and can take responsibility for the integrity of the data and the accuracy of data analysis.

**Competing interests declaration**

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: MHG, MV, JM, and LIB had financial support from the Research Council of Norway (grant number 273581), for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; IVV reports receiving honorarium as editor of the American Journal of Geriatric Psychiatry.

**Data sharing**

Relevant anonymised data are available at reasonable request. Data are fully available to collaborators and affiliated researchers.

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**Dissemination declaration**

The results of this study will be disseminated to relevant user organisations (Norwegian Health Organisation), participants, affiliated health care personnel and external healthcare workers, as well as health authorities.

**FIGURE LEGENDS**

**Figure 1: The parent study, LIVE@Home.Path, including PAN.DEM.** The covid-19 restrictions replaced trial protocol from 12 Mar. until eased on 15 May 2020. None of the dyads (persons with dementia and informal carers, n) received the intervention whilst the PAN.DEM interviews were conducted (20 Apr. to 15 May 2020). **Panel a: Timeline.** Vertical lines indicate assessments. The shaded parts illustrate the covid-19 restrictions, postponing the LIVE-Intervention (Learning, Innovation, Volunteers, and Empowerment) for the dyads of Group 2. **Panel b: Flowchart.** This study includes the dyads of PAN.DEM completing the pre-pandemic assessment before the covid-19 restrictions was implemented on 12 Mar. 2020.

**Figure 2: Change in behavioural and psychological symptoms in n (%) persons with dementia from the pre-pandemic to the pandemic assessment.** n: 104. Pre-pandemic: Six-month assessment of parent study (12 Dec. 2019 to 11 Mar. 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). Neuropsychiatric Inventory, subsyndrome score: psychosis (delusions and hallucinations), hyperactive behaviour (agitation, euphoria, irritation, disinhibition, aberrant motor behaviour), mood (depression, apathy, sleep disturbances, and appetite changes). Cornell Scale for Depression in Dementia, total score.

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Figure 1, Panel a

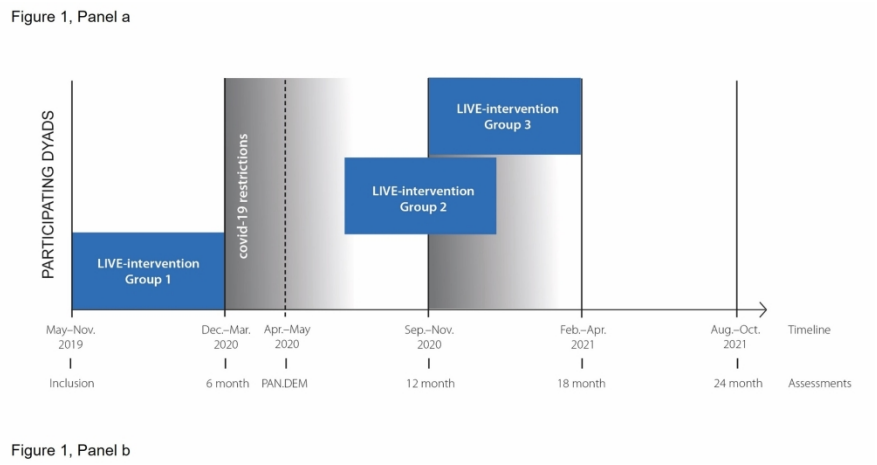


Figure 1, Panel b

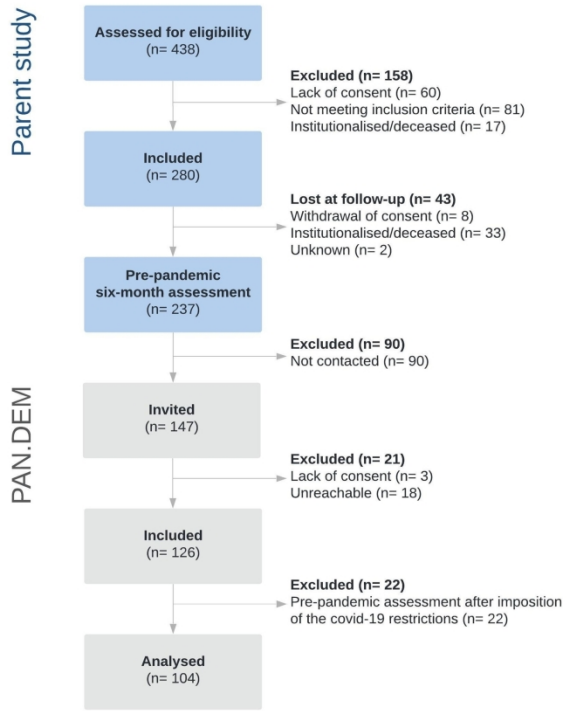


**Figure 1: The parent study, LIVE@Home.Path, including PAN.DEM.** The covid-19 restrictions replaced trial protocol from 12 Mar. until eased on 15 May 2020. None of the dyads (persons with dementia and informal carers, n) received the intervention whilst the PAN.DEM interviews were conducted (20 Apr. to 15 May 2020). **Panel a:Timeline.** Vertical lines indicate assessments. The shaded parts illustrate the covid-19 restrictions, postponing the LIVE-Intervention (Learning, Innovation, Volunteers, and Empowerment) for the dyads of Group 2. **Panel b: Flowchart.** This study includes the dyads of PAN.DEM completing the pre-pandemic assessment before the covid-19 restrictions was implemented on 12 Mar. 2020.

217x296mm (300 x 300 DPI)

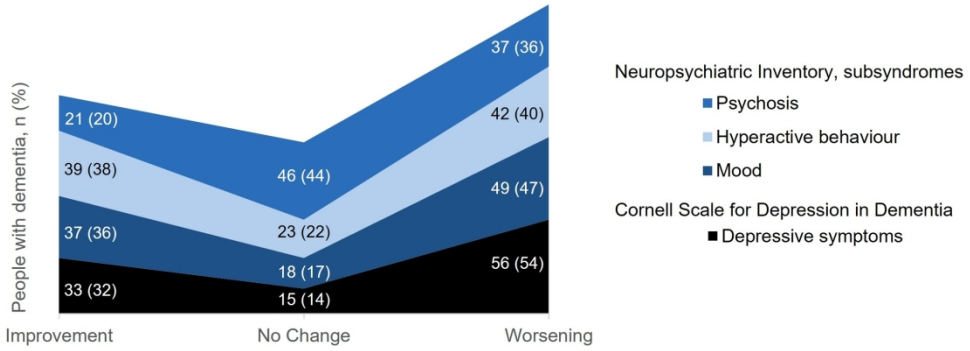


**Figure 2: Change in behavioural and psychological symptoms in n (%) persons with dementia from the pre-pandemic to the pandemic assessment.** n: 104. Pre-pandemic: Six-month assessment of parent study (12 Dec. 2019 to 11 Mar. 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). Neuropsychiatric Inventory, subsyndrome score: psychosis (delusions and hallucinations), hyperactive behaviour (agitation, euphoria, irritation, disinhibition, aberrant motor behaviour), mood (depression, apathy, sleep disturbances, and appetite changes). Cornell Scale for Depression in Dementia, total score.

191x80mm (300 x 300 DPI)

# The PAN.DEM assessment

Respondents: informal carers in the LIVE@Home.Path trial

1 **Date of birth:** mm.dd.yyyy

2 **Are you temporarily laid off due to the covid-19 restrictions?**

- ☐ Yes
- ☐ No
- ☐ Not applicable

3 **During the last month, have you been quarantined due to covid-19?**

- ☐ Yes
- ☐ No

**If yes, please specify:**

_____

4 **Does the person with dementia have insight into the covid-19 situation?**

- ☐ To no degree
- ☐ Partial
- ☐ Sufficient

5 **To what degree are you concerned that the person with dementia will be infected with covid-19?**

Tick a number on the scale from 0-10 (0=not at all; 10=as much as possible):

0 1 2 3 4 5 6 7 8 9 10

6 **To what degree are you concerned that you yourself will be infected with covid-19?**

Tick a number on the scale from 0-10 (0=not at all; 10=as much as possible)

0 1 2 3 4 5 6 7 8 9 10

7 **To what degree are you concerned that you yourself will be infected with covid-19?**

Tick a number on the scale from 0-10: (0=not at all; 10=as much as possible):

0 1 2 3 4 5 6 7 8 9 10

8 **To what degree are your concern for own infection sourced from your responsibilities as carer?**

Tick a number on the scale from 0-10:(0=not at all; 10=as much as possible):

0 1 2 3 4 5 6 7 8 9 10

9 **As a response to the covid-19 pandemic, did you discuss advanced care planning with the person with dementia?** If yes, please specify below.

_____

10 **Did the covid-19 restrictions have any consequences for the healthcare services provided by the municipality for the person with dementia** (e.g. home nursing services, activity groups, day care centre, respite care).

☐ Yes

☐ No

**If yes, specify per Resource Utilization in Dementia Version 4 section A2.2.5** [1 2]

11 **Have you avoided or postponed contacts with health care professionals due to the COVID-19 pandemic and the restrictions?**

☐ Yes

☐ No

**If yes, please specify:**

_____

12 **Informal care time assessed by Resource Utilization in Dementia Version 4 section B1.2** [1 2]

13 **Has the food habits and appetite of the person with dementia changed under to the covid-19 restrictions?**

☐ Yes
☐ No

**If yes, please specify:** Tick one or several items.

☐ Eats/drinks less
☐ Loss of appetite
☐ Eats more
☐ Eats mote unhealthy food
☐ Has stopped preparing food him/herself
☐ Heats prepared food
☐ Is unable to maintain diet without help from informal or formal carers

14 **Neuropsychiatric inventory (12 item version)** [3]

15 **Cornell Scale of Depression in Dementia** [4]

16 **Has the pandemic had any consequences for services provided by volunteers?**

☐ Yes
☐ No

**If yes, specify as applicable:**

_____

17 **Has the covid-19 restrictions increased your interest in assistive technology?**

☐ Yes
☐ No

**If yes, specify as applicable** including complaint/need, type of technology, if acquired, including privately financed or municipally funded:

_____

18 **Compared to pre-pandemic levels, what sort of contact have you had with the person with dementia?** Tick one or several items.

- ☐ Unchanged
- ☐ Increased
- ☐ Reduced
- ☐ No contact at all
- ☐ More digital contact

19 **Have you implemented measures and restrictions to prevent transmission of covid-19 to the person with dementia?** Please specify as applicable:

_____

20 **Compared to immediately before the pandemic, how would you rank your own total situation as a carer?** [5]

Tick a number from -5 (much worse) to 5 (much better), via 0 (no change).

-5 -4 -3 -2 -1 0 1 2 3 4 5

21 **Do you have any additional comments?** Please specify as applicable:

_____



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Supplementary table A: Pre-pandemic compared to pandemic item scores of Cornell Scale of Depression in Dementia for the 104 persons with dementia.

| | Pre-pandemic | | Pandemic | | P |
|---|---|---|---|---|---|
| | mean | SD | mean | SD | |
| Anxiety | 0.48 | 0.62 | 0.51 | 0.72 | 0.64 |
| Sadness | 0.42 | 0.62 | 0.51 | 0.69 | 0.36 |
| Lack of reactivity to pleasant events | 0.25 | 0.50 | 0.27 | 0.57 | 0.44 |
| Irritability | 0.55 | 0.70 | 0.62 | 0.70 | 0.58 |
| Agitation | 0.15 | 0.48 | 0.25 | 0.58 | 0.24 |
| Retardation | 0.35 | 0.64 | 0.50 | 0.75 | 0.06 |
| Multiple physical complaints | 0.39 | 0.65 | 0.59 | 0.76 | 0.02* |
| Loss of interest | 0.44 | 0.75 | 0.65 | 0.72 | 0.04* |
| Appetite loss | 0.39 | 0.67 | 0.30 | 0.61 | 0.12 |
| Weight loss | 0.19 | 0.51 | 0.26 | 0.55 | 0.13 |
| Lack of energy | 0.74 | 0.79 | 0.92 | 0.80 | 0.14 |
| Diurnal variation of mood | 0.32 | 0.62 | 0.40 | 0.62 | 0.16 |
| Difficulty falling asleep | 0.18 | 0.47 | 0.19 | 0.48 | 0.85 |
| Multiple awakenings | 0.31 | 0.64 | 0.37 | 0.62 | 0.21 |
| Early morning awakenings | 0.25 | 0.57 | 0.24 | 0.53 | 0.85 |
| Suicidal ideation | 0.15 | 0.41 | 0.21 | 0.48 | 0.23 |
| Self-depreciation | 0.34 | 0.57 | 0.32 | 0.57 | >0.99 |
| Pessimism | 0.37 | 0.65 | 0.44 | 0.65 | 0.18 |
| Mood congruent delusions | 0.25 | 0.57 | 0.32 | 0.60 | 0.14 |

Table legend:

Pre-pandemic: Six-month assessment of the parent study (12 Dec. 2019 to 11 Mar. 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). SD: standard deviation. P: P values for difference between time points by the paired t-test, * indicates two-tailed P<.05. Carers rated items ‘absent’ to ‘severe’ (0-2).

Supplementary table B: Post-hoc analysis of associations between worsening behavioural and psychological symptoms (from the pre-pandemic to the pandemic assessment) and pre-pandemic traits for the 104 persons with dementia.

| | mean (SD) | P |
|---|---|---|
| Worsening psychosis subsyndrome | | |
| Use of antipsychotic drugs (N05A) | | |
| Yes | 0.33 (0.52) | 0.92 |
| No | 0.36 (0.48) | |
| Receiving the LIVE-intervention | | |
| Yes | 0.29 (0.46) | 0.45 |
| No | 0.37 (0.49) | |
| Worsening depressive symptoms | | |
| Use of antidepressant drugs (N06A) | | |
| Yes | 0.63 (0.50) | 0.88 |
| No | 0.61 (0.49) | |
| Receiving the LIVE-intervention | | |
| Yes | 0.62 (0.50) | 0.97 |
| No | 0.61 (0.49) | |

Table legend:

Pre-pandemic: Six-month assessment of the parent study (12 Dec 2019 to 11 Mar 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 15 2020). SD: standard deviation. P: P values for difference between groups by unequal variances t-test, * indicates two-tailed P<.05. Psychosis subsyndrome constituting delusions and hallucinations by the Neuropsychiatric Inventory. Depressive symptoms by Cornell Scale of Depression in Dementia. LIVE-intervention: Multicomponent intervention of the parent study comprising Learning, Innovation, Volunteers, and Empowerment. Drugs classified by the Anatomical Therapeutic Chemical Index.

STROBE Statement—checklist of items that should be included in reports of observational studies

| | Item No | Recommendation | Page in manuscript |
|---|---|---|---|
| **Title and abstract** | 1 | (*a*) Indicate the study's design with a commonly used term in the title or the abstract | Page 1 and 2 |
| | | (*b*) Provide in the abstract an informative and balanced summary of what was done and what was found | Page 2 |
| **Introduction** | | | |
| Background/rationale | 2 | Explain the scientific background and rationale for the investigation being reported | Page 3 and 4 |
| Objectives | 3 | State specific objectives, including any prespecified hypotheses | Page 3 and 4 |
| **Methods** | | | |
| Study design | 4 | Present key elements of study design early in the paper | Page 4 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | Page 4 |
| Participants | 6 | (*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up<br>*Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls<br>*Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants | Page 4 and figure 1 |
| | | (*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed<br>*Case-control study*—For matched studies, give matching criteria and the number of controls per case | Not applicable |
| Variables | 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | Page 4 and 5 |
| Data sources/ measurement | 8* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | Page 4 and 5 |
| Bias | 9 | Describe any efforts to address potential sources of bias | Page 12 |
| Study size | 10 | Explain how the study size was arrived at | Page 4 and 12 |
| Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why | Page 5 and 6 |
| Statistical methods | 12 | (*a*) Describe all statistical methods, including those used to control for confounding | Page 5 and 6 |
| | | (*b*) Describe any methods used to examine subgroups and interactions | Page 5, 6 and 12 |
| | | (*c*) Explain how missing data were addressed | Page 6 |
| | | (*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed<br>*Case-control study*—If applicable, explain how matching of cases and controls was addressed | Not applicable |

| | | | |
|---|---|---|---|
| | | *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy | |
| | | (*e*) Describe any sensitivity analyses | Page 12 |
| **Results** | | | |
| Participants | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed | Page 6 and figure 1 |
| | | (b) Give reasons for non-participation at each stage | Figure 1 |
| | | (c) Consider use of a flow diagram | Figure 1 |
| Descriptive data | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders | Page 6, table 1, table 2 |
| | | (b) Indicate number of participants with missing data for each variable of interest | Page 6 |
| | | (c) *Cohort study*—Summarise follow-up time (eg, average and total amount) | Page 6 |
| Outcome data | 15* | *Cohort study*—Report numbers of outcome events or summary measures over time | Page 9, table 3 |
| | | *Case-control study*—Report numbers in each exposure category, or summary measures of exposure | |
| | | *Cross-sectional study*—Report numbers of outcome events or summary measures | |
| Main results | 16 | (*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | Page 9 and 10, table 3 and 4 |
| | | (*b*) Report category boundaries when continuous variables were categorized | Page 5 |
| | | (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | |
| Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses | Page 12 |
| **Discussion** | | | |
| Key results | 18 | Summarise key results with reference to study objectives | Page 12 |
| Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | Page 12 and 13 |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | Page 12-14 |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results | Page 13 and 14 |
| **Other information** | | | |
| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | Page 14 |

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

# The impact of covid-19 restrictions on behavioural and psychological symptoms in home-dwelling people with dementia: a prospective cohort study (PAN.DEM)

| | |
|---|---|
| Journal: | *BMJ Open* |
| Manuscript ID | bmjopen-2021-050628.R1 |
| Article Type: | Original research |
| Date Submitted by the Author: | 15-Sep-2021 |
| Complete List of Authors: | Gedde, Marie; University of Bergen, Department of Global Public Health and Primary Care; Haraldsplass Diakonale Sykehus AS,<br>Husebo, Bettina; University of Bergen, Department of Global Public Health and Primary Care; Bergen Municipality<br>Vahia, Ipsit ; McLean Hospital; Harvard Medical School<br>Mannseth, Janne ; University of Bergen, Department of Global Public Health Primary Care, Faculty of Medicine, University of Bergen, Bergen, Norway<br>Vislapuu, Maarja; University of Bergen, Department of Global Public Health and Primary Care<br>Naik, Mala; Haraldsplass Diakonale Sykehus AS, Medical Clinic; University of Bergen, Department of Clinical Science<br>Berge, Line ; NKS Olaviken Gerontopsychiatric Hospital; University of Bergen, Department of Global Public Health Primary Care, Faculty of Medicine, University of Bergen, Bergen, Norway |
| Primary Subject Heading: | Neurology |
| Secondary Subject Heading: | Health policy, Geriatric medicine, Mental health, General practice / Family practice |
| Keywords: | Dementia < NEUROLOGY, COVID-19, Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Old age psychiatry < PSYCHIATRY, PRIMARY CARE |
| | |

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# The impact of covid-19 restrictions on behavioural and psychological symptoms in home-dwelling people with dementia: a prospective cohort study (PAN.DEM)

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Word count: 2,802

## ABSTRACT

**Objectives**: To investigate the impact of the covid-19 restrictions on behavioural and psychological symptoms of dementia (BPSD).

**Design**: Prospective cohort study (PAN.DEM) nested within the halted parent trial (LIVE@Home.Path).

**Setting**: Households in municipalities in Norway immediate before and six to nine weeks into the covid-19 restrictions.

**Participants**: 104 dyads (persons with mild to moderate dementia aged ≥65 and their informal carers) completed both pre- and pandemic assessments amongst 237 in the parent trial. Mini-Mental Status Examination (MMSE) score 15-26 or Functional Assessment Scaling (FAST) score 3-7 covered dementia severity.

**Main outcome measures**: Neuropsychiatric Inventory (NPI-12) total (range 0-144), psychosis (range 0-24), hyperactive behaviour (range 0-60), and mood subsyndrome (range 0-48) scores; Cornell Scale for Depression in Dementia (CSDD) total score (range 0-38).

**Results**: We found an overall increase in BPSD by NPI-12 total score comparing pre-pandemic to pandemic levels (median 16 interquartile range [4.5, 29] to 20 [7, 32.5], P=0.03). NPI-12 total score worsened in 57 (55%) of people with dementia and was associated with postponed or averted contacts with health care professionals (logistic regression, odds ratio 3.96, 95% confidence interval 1.05 to 14.95). Psychosis subsyndrome levels increased (0 [0, 3] to 0.5 [0, 6], P=0.01) in 37 (36%) persons; this worsening was associated with partial insight (9.57, 1.14 to 80.71) and reduced carer contact (4.45, 1.01 to 19.71). Moreover, depressive symptoms increased as assessed by CSDD total score (5 [3, 9] to 7 [4, 12], P=0.01) and worsened for 56 (54%), which was inversely associated with psychotropic drugs on-demand (0.16, 0.03 to 0.75).

**Conclusions**: BPSD worsened during the first two months of the covid-19 restrictions, most pronounced for psychosis and depression. These BPSD exacerbations have implications for pandemic policies globally, emphasising that restrictions must balance covid-19 morbidity and mortality against dementia deterioration.

**Registration**: ClinicalTrials.gov; NCT04043364.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- This is the first prospective cohort study investigating the impact of the covid-19 restrictions on behavioural and psychological symptoms of dementia (BPSD).
- The same carers reported BPSD for each home-dwelling person with dementia both before and during the pandemic scenario using validated, well-established instruments.
- The covid-19 restrictions left some carers with less basis of observation, as 28% reported reduced contact with the person with dementia.
- Our study captures the impact of the initial phase of the outbreak in Norway and does not describe the long-term impact of the covid-19 restrictions on BPSD.

## INTRODUCTION

Dementia is among the most critical risk factors for covid-19 mortality.[1] In England and Wales alone, 12,869 people with dementia have died, accounting for 26% of the covid-19 death toll.[2] Until vaccination is widely available globally, hygiene and physical distancing interventions will remain cornerstones of protecting vulnerable populations.[3] The subsequent restrictions have been disrupting for home-dwelling people with dementia as private homes were not accessible to family members and volunteers, day care centres closed, and home nursing services were restricted to those most in need. As a result, people with dementia living in the community are not only at risk from covid-19 morbidity and mortality; they are also threatened from unforeseen effects of the restrictions.[4, 5]

Behavioural and psychological symptoms of dementia (BPSD) cover a wide range of clinical presentation including depression, anxiety, agitation, and psychosis. Longitudinally, persistent BPSD may be found in up to 80% of people with dementia.[6] BPSD are best managed with structured, non-pharmacological interventions, placing psychotropic drugs as secondary treatment options.[7] Preliminary evidences indicate that BPSD may be exacerbated under the covid-19 restrictions. Eight weeks into the Argentinian quarantine, informal carers reported worsening of anxiety, insomnia, and depression among persons at different stages of Alzheimer's and related dementias living at home (N=119).[8] In another study, family carers stated worsening BPSD in 60% of Italian outpatients with various stages and aetiologies of dementia one month into the pandemic (N=4,913).[9] This study also found that 28% required changes in psychotropic medication to address irritability, apathy, agitation, and depression. Further, nursing home patients separated from the outside world in France with mild Alzheimer's disease reported increased anxiety and depression when asked to evaluate their own experience of the pandemic retrospectively (N=58).[10]

However, all these studies are cross-sectional and thus far, there is a dearth of longitudinal data tracking changes in BPSD during covid-19 by comparing pre-pandemic to pandemic rates.[11] In this study, we aim to address this significant gap in the literature using data from the prospective PAN.DEM study.[12] This study is nested within the ongoing LIVE@Home.Path trial[13] and was launched by our team to investigate the impact of the covid-19 restrictions (implemented in Norway on 12 Mar. 2020) on home-dwelling people with dementia. Here we present comparisons of pre-pandemic and pandemic BPSD, and explore factors associated with worsening BPSD.

## METHODS

The parent trial, LIVE@Home.Path, is a stepped-wedge randomised controlled trial.[13] It compares the cost-effectiveness in resource utilisation of a six-month multicomponent intervention comprising Learning, Innovation, Volunteers, and Empowerment (LIVE) to usual conditions for dyads of home-dwelling people with dementia and their informal carers. Dyads were eligible for inclusion if the persons with dementia were: ≥65 years, diagnosed with dementia (with Mini-Mental Status Examination (MMSE) score 15-26 or Functional Assessment Scaling (FAST) score 3-7);[14, 15] home-dwelling in one of three Norwegian municipalities; and had weekly face-to-face contact with the carer. Trained data collectors blindly assessed all dyads in direct conversation every six months for two years (2019 to 2021). The pre-pandemic six-month assessment was close to complete when the covid-19 restrictions replaced trial protocol (figure 1, panel a). Physical distancing (i.e., restrictions on gatherings, public transport closure, stay at home-regulations, and limitations on movement) formed the basis for the restrictions,[3] which implied that health care was limited to those most in need.[12] In response, we developed the semi-structured PANdemic in DEMentia (PAN.DEM) telephone interview for carers to capture if, and how, dyads were affected by the outbreak (supplementary file). This assessment included selected instruments from the parent trial in addition to questions regarding the pandemic. We consecutively invited as many dyads as possible from the parent trial to complete the PAN.DEM assessment from week six of restrictions until eased the ninth week (20 Apr. to 15 May 2020). Potential respondents were considered unreachable when no response was given to two calls and a text message.

This study compares the pre-pandemic assessment of the parent trial to the PAN.DEM assessment (figure 1, panel b).

*Figure 1 here*

**Assessments**

The primary outcome was change in BPSD between the pre-pandemic and pandemic assessments. We administered two carer-rated scales at both time points. 1) The Neuropsychiatric Inventory (NPI-12) assesses frequency and severity of delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibitions, irritability, aberrant motorial behaviour, sleep disturbances, and appetite changes over the four preceding weeks.[16] Each of these twelve domains is scored from 0 (no symptoms) to 12 (very severe symptoms), a score ≥4 is regarded a BPSD with symptom load of clinical relevance. These domains are further aggregated to generate subsyndrome scores for psychosis comprised of delusions and hallucinations (0-24), hyperactive behaviour comprised of agitation, euphoria, irritation, disinhibition, aberrant motor behaviour (0-60), mood comprised of depression, apathy, sleep disturbances, and appetite changes (0-48), and finally, a total NPI-12 score (0-144).[17] 2) The Cornell Scale for Depression in Dementia (CSDD) assesses nineteen items of depressive symptoms during the prior week, each rated from 'absent' to 'severe' (0-2), or 'symptoms not possible to evaluate' (missing).[18] Adding item scores generate the CSDD total score (0-38).[18] The Norwegian versions of NPI-12 and CSDD have robust psychometric properties.[16, 18-20]

In addition to BPSD, we collected the following data at the pre-pandemic assessment: the persons with dementia's level of functioning in activities of daily living by Physical Self-Maintenance Scale (PSMS)[21] and Instrumental Activities of Daily Living Scale (IADL),[22] health by the General Medical Health Rating Scale (GMHR),[23] possible dementia aetiology following the International Classification of Diseases – 10$^{th}$ version (ICD-10),[24] and use of health care services and medications as specified by the dyads. Drugs catalogued in the Anatomical Therapeutic Chemical Index (ATC) administered in a set schedule were regarded 'regular', whereas all others were documented as 'on demand'.[25] Psychotropic drugs included antipsychotic (N05A), anxiolytic (N05B), hypnotic and sedative (N05C), antidepressant (N06A), and anti-dementia drugs (N06D) by ATC. Demographical data (age, gender, residency, kinship) were self-reported. We evaluated dementia severity in terms of cognition with MMSE and level of functioning with FAST at inclusion.[14, 15]

At the pandemic assessment, the carers were also asked to estimate the degree of insight presented by the person with dementia into the covid-19 situation and change in 1) contact with the carer, 2) volunteering services, and 3) municipal health care services (home nursing services, home help, day-care, and in-home and out-of-home respite care) due to the covid-19 restrictions.[12] Finally, carers stated if contacts with health care professionals were postponed or averted.

### Statistical analysis

Initially, we aggregated median and interquartile range (IQR), and calculated NPI-12 subsyndrome scores and total scores for NPI-12 and CSDD if >80% of the scales were answered. We used the Wilcoxon matched-pairs signed-rank test to assess change between the pre- and pandemic assessments. Next, we dichotomized those NPI-12 and CSDD sum scores that changed into worsening/not worsening and utilized multiple logistic regression analysis to explore factors associated. We included the following covariates for persons with dementia: age, gender, residency, dementia aetiology, MMSE, FAST, IADL, PSMS, GMHR, number of psychotropic drugs prescribed regularly and on-demand, the covid-19 specific outcomes. We also included age and gender of the carers. Missing data were handled with listwise deletion, with 14% missing any covariates. The Akaike information criterion guided the model selection. Selected models were checked for multicollinearity, robustness, and goodness-of-fit by Pearson and Hosmer-Lemeshow test. Calculations are expressed in odds ratio (OR) with 95% confidence intervals (95%CI), and P value. Reported P values are two-tailed, and $P<0.05$ was considered statistically significant. Descriptive statistics are presented by n (%), mean and standard deviation (SD), or median [IQR]. We used Stata/IC, release 16 (StataCorp LP, College Station, TX) for all analyses.

### Ethics

Dyads gave informed spoken and written consent for participation in the parent trial as described in the protocol.[13] Carers gave additional informed consent to PAN.DEM.[12] The Regional Committee for Medical and Health Research Ethics North Norway approved the parent trial (2019/385) and PAN.DEM (10861) before data was collected.

### Public and Patient Involvement

The conceptualisation, design, assessments, and conduct of the parent trial as well as PAN.DEM included close patient/carer and public involvement.[12, 13] A user-representative participated in the research group's weekly meetings. In PAN.DEM, he consulted with the study team on priorities, length, and wording of the interview, and its revisions, with a special focus on the potential burden on carers.[12]

## RESULTS

Of the 280 dyads participating in the parent trial, 237 completed the pre-pandemic assessment from Dec. 2019 to Mar. 2020 (figure 1, panel b). This study includes 104 dyads recruited to PAN.DEM completing the pre-pandemic assessment before the covid-19 restrictions were effectuated 12 Mar. 2020. Mean time between assessments was 86 days (SD 19).

Table 1 shows that the mean age for people with dementia was 82 years (SD 7), 61% were women, 44% lived alone, and 50% received daily home-nursing services prior to the covid-19 restrictions. Alzheimer's disease constituted the most common dementia aetiology, while 6% had vascular dementia and 10% reported Lewy-body dementia or Parkinson's disease. Most people with dementia lacked insight into the covid-19 situation (table 2). The carers reported to have less contact with the person with dementia in 28% under the restrictions, and that contacts with health care professionals had been postponed or averted in 31%.

Table 1: Pre-pandemic characteristics for the 104 dyads (persons with dementia and informal carers, n).

| | n (%) | median [IQR] |
|---|---|---|
| *Person with dementia* | | |
| Age, mean (SD) | | 82 (7) |
| Gender, Female | 63 (61) | |
| Residency | | |
| Living alone | 46 (44) | |
| Coresiding with the reporting carer | 46 (44) | |
| Coresiding with someone else than the carer | 12 (12) | |
| Dementia aetiology | | |
| Alzheimer's Disease | 45 (43) | |
| Vascular Dementia | 6 (6) | |
| Dementia in other diseases classified elsewhere | 10 (10) | |
| Unspecified Dementia | 43 (41) | |
| MMSE, range 0-30 | | 21 [18, 24] |
| FAST, range 1-7 | | 4 [4, 4] |
| GMHR, range 1-4 | | 3 [2, 3] |
| PSMS, range 6-30 | | 11 [9, 14] |
| IADL, range 8-31 | | 22 [18, 27] |
| Drugs in general | | |
| Total number | | 6 [4, 8] |
| Regularly | | 5 [3, 7] |
| Psychotropic drugs | | |
| Total number | | 1 [0, 2] |
| Regularly | | 1 [0, 1] |
| Antipsychotic drugs (N05A) | 6 (6) | |
| Anxiolytic drugs (N05B) | 3 (3) | |
| Hypnotic/sedative drugs (N05C) | 10 (10) | |
| Antidepressant drugs (N06A) | 19 (18) | |
| Anti-dementia drugs (N06D) | 52 (50) | |
| On-demand | | 0 [0, 0] |

| | | |
|---|---|---|
| Antipsychotic drugs (N05A) | 0 (0) | |
| Anxiolytic drugs (N05B) | 5 (5) | |
| Hypnotic/sedative drugs (N05C) | 12 (12) | |
| Antidepressant drugs (N06A) | 0 (0) | |
| Anti-dementia drugs (N06D). | 0 (0) | |
| Health care services | | |
| Daily Home Nursing | 52 (50) | |
| Weekly Day Care | 29 (28) | |
| Respite Care (In-Home and Out-of-Home) | 2 (2) | |
| Volunteering services | 8 (8) | |
| *Carer* | | |
| Age, mean (SD) | | 65 (12) |
| Gender, Female | 68 (65) | |
| Kinship to the person with dementia | | |
| Spouse | 44 (42) | |
| Child | 58 (56) | |
| Others | 2 (2) | |

Table 1 legend:
Pre-pandemic: Six-month assessment of parent trial (12 Dec. 2019 to 11 Mar. 2020). IQR: interquartile range. SD: Standard deviation. ICD-10: International Statistical Classification of Diseases and Related Health Problems. MMSE: Mini-Mental Status Examination, at inclusion. FAST, Functional Assessment Scaling, at inclusion. GMHR: General Medical Health Rating Scale. PSMS: Physical Self-Maintenance Scale. IADL: Instrumental Activities of Daily Living Scale. Drugs were classified by the Anatomical Therapeutic Chemical Index; antipsychotics, anxiolytics, hypnotics/sedatives, antidepressants, and anti-dementia drugs constituted psychotropic drugs.

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Table 2: Pandemic characteristics for the 104 persons with dementia (n) as perceived by their carers.

| | n (%) |
|---|---|
| Degree of insight | |
| Sufficient | 34 (33) |
| Partial | 54 (52) |
| To no degree | 16 (15) |
| Change in contact with the carer# | |
| Reduced | 29 (28) |
| No change | 49 (47) |
| Increased | 23 (22) |
| Ceased volunteering services# | 8 (8) |

| | |
|---|---|
| Change in health care services# | 42 (40) |
| Postponed or averted contacts with health care professionals# | 32 (31) |

Table 2 legend:
Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). # relative the pre-pandemic situation. Health care services provided by the municipality: home nursing services, home help, day-care, and respite care (In-Home and Out-of-Home).

From the pre- to the pandemic assessment, people with dementia experienced an increase in NPI-12 total score (16 [4.5, 29] to 20 [7, 32.5], P=0.03) and in numbers of BPSD with symptom load of clinical relevance (2 [0, 4] to 3 [1, 5], P<0.001) (table 3). Also, the NPI-12 score worsened for 55% (figure 2). We found an increase in the psychosis subsyndrome (0 [0, 3] to 0.5 [0, 6], P=0.01), with 36% experiencing more severe symptoms (figure 2). We also found an increase in depressive symptoms measured both by the NPI-12 depression domain (0 [0, 3] to 1 [0, 6], P=0.04) and CSDD total score (5 [3, 9] to 7 [4, 12], P=0.01, table 3). Additionally, the CSDD total score worsened for 54% (figure 2).

Table 3: Pre-pandemic compared to pandemic levels of behavioural and psychological symptoms (BPSD) for the 104 persons with dementia (n).

| | Pre-pandemic | | Pandemic | | |
|---|---|---|---|---|---|
| | median | IQR | median | IQR | P |
| *Neuropsychiatric inventory (NPI-12)* | | | | | |
| Total score, range 0-144 | 16 | [4.5, 29] | 20 | [7, 32.5] | 0.03* |
| Subsyndromes | | | | | |
| Psychosis, range 0-24 | 0 | [0, 3] | 0.5 | [0, 6] | 0.01* |
| Hyperactive behaviour, range 0-60 | 5.5 | [0, 12] | 4 | [0, 12] | 0.79 |
| Mood, range 0-48 | 6 | [0, 12] | 6.5 | [1, 12] | 0.21 |
| Domain scores, range 0-12 | | | | | |
| Delusions | 0 | [0, 2] | 0 | [0, 6] | 0.04* |
| Hallucinations | 0 | [0, 0] | 0 | [0, 0] | 0.23 |
| Agitation | 0 | [0, 3] | 0 | [0, 2] | 0.45 |
| Depression | 0 | [0, 3] | 1 | [0, 6] | 0.04* |
| Anxiety | 0 | [0, 2] | 0 | [0, 4] | 0.07 |
| Euphoria | 0 | [0, 0] | 0 | [0, 0] | 0.19 |
| Apathy | 0 | [0, 4] | 0 | [0, 4] | 0.50 |

| | | | | | |
|---|---|---|---|---|---|
| Disinhibitions | 0 | [0, 0] | 0 | [0, 1.5] | 0.16 |
| Irritability | 0 | [0, 4] | 0 | [0, 4] | 0.78 |
| Aberrant motor behaviour | 0 | [0, 1] | 0 | [0, 2.5] | 0.66 |
| Sleep disturbances | 0 | [0, 3] | 0 | [0, 4] | 0.82 |
| Appetite changes | 0 | [0, 1] | 0 | [0, 1] | 0.84 |
| Number of BPSD with symptom load of clinical relevance (NPI-12 domain score ≥4), range 0-12 | 2 | [0, 4] | 3 | [1, 5] | <0.001* |
| *Cornell Scale for Depression in Dementia* | | | | | |
| Total score, range 0-38 | 5 | [3, 9] | 7 | [4, 12] | 0.01* |

Table 3 legend:
Pre-pandemic: Six-month assessment of parent trial (12 Dec. 2019 to 11 Mar. 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). IQR: Interquartile range. P: P value for difference between time points by the Wilcoxon matched-pairs signed-rank test, * indicates two-tailed P <0.05. NPI-12 subsyndromes: psychosis (delusions and hallucinations), hyperactive behaviour (agitation, euphoria, irritation, disinhibition, aberrant motor behaviour), mood (depression, apathy, sleep disturbances, and appetite changes).

*Figure 2 here*

The supplementary table A shows the results of the logistic regression models exploring factors associated with worsening BPSD under the restrictions. Worsening NPI-12 total score was associated with postponed or averted contacts with health care professionals (OR 3.96, 95%CI 1.05 to 14.95) and impaired cognition as indicated by MMSE (OR 1.19, 95% CI 1.01 to 1.40), while a diagnosis of Alzheimer's disease relative to other dementia aetiologies was associated with lower OR of worsening NPI-12 (OR 0.18, 95%CI 0.05 to 0.63). Worsening psychosis subsyndrome score was associated with partial insight into the covid-19 situation (OR 9.57, 95%CI 1.14 to 80.71), reduced contact with the carer (OR 4.45, 95%CI 1.01 to 19.71), and impaired function as indicated by FAST (OR 2.59, 95%CI 1.07 to 6.27). An inverse association occurred for higher dependency in activities of daily living by PSMS and worsening psychosis subsyndrome (OR 0.68, 95%CI 0.51 to 0.91). Worsening depressive symptoms was associated with impaired function by FAST (OR 4.96, 95%CI 1.57 to 15.65), in contrast to lower odds associated with Alzheimer's disease (OR 0.21, 95%CI 0.05 to 0.85) and psychotropic drug use on-demand (OR 0.16, 95%CI 0.03 to 0.75).

Post-hoc analysis did not show any association between use of antipsychotic drugs before the restrictions and worsening psychosis subsyndrome using unequal variances t-test (supplementary table B). Similarly, we found no association between use of antidepressants and worsening depressive symptoms. Neither randomisation to the intervention vs. control of the parent trial showed associations with worsening NP-12 total score, psychosis subsyndrome nor depressive symptoms (supplementary table B). To explore if consecutive sampling introduced bias, we compared our study sample to those not included yet still in parent trial at the pre-pandemic assessment, revealing minimal differences (supplementary table C).

## DISCUSSION

Our primary aim was to compare pre- and pandemic levels of BPSD in home-dwelling people with dementia during the two first months of covid-19 restrictions in Norway. We found an overall increase in BPSD, and that odds of worsening were four times higher with postponed or averted contacts with health care professionals. More specifically, the increase was most pronounced for symptoms of psychosis and depression. The odds for worsening psychosis increased ten-fold with partial insight into the covid-19 situation and four-fold with reduced contact with carers, while as-needed use of psychotropic drugs was associated with fewer depressive symptoms.

### Strengths and weaknesses

Our study provides prospective data obtained shortly before and under the covid-19 restrictions rated by the same carer for each subject and based on extensive assessor-blinded interviews with validated, well-established instruments.[12, 13] The parent trial population was recruited from different municipalities to be representative to the Norwegian demographic in terms of dementia aetiology, severity, and symptomatology.[13] As our study sample was fairly similar to those dyads not included from the parent trial, we argue that our study was not biased by selection.

There are weaknesses to address. Despite efforts, we were not able to contact all potential respondents through consecutive sampling before the restrictions were eased for the first time, explaining the limited sample size. NPI-12 and CSDD are not validated for telephone interviews.[16, 18] Previous work has shown that carer psychosocial factors such as sense of competence, guilt, and relationship quality account for up to 56% of the variance in BPSD-related distress.[26] In the case of the pandemic, stress-related symptoms were experienced by two-thirds of family carers soon after the outbreak hit Italy (N=4,913) and were associated with incident or worsening BPSD.[9] The authors conclude that they could not determine whether increased BPSD were the cause or consequence of carer distress, as both

counterparts were exposed to similar conditions during quarantine. Even though we did not assess such domains, these considerations apply to our study. Another point is that 28% of the carers reported reduced contact with the person with dementia, leaving them with less clinical observation. As 44% of the dyads were not living together, we suggest that some violated the restrictions to visit their loved ones and keep their obligations as careers, possibly mitigating the impact on BPSD. These weaknesses should be considered when interpreting the results, along with the wide confidence intervals of the covariates associated with worsening BPSD. Notably, our data capture the impact of the initial phase of the outbreak in Norway and can therefore not answer longer-term consequences from either reimposition or lengthening of invasive restrictions.

**Comparison with other studies**

This study provides data to demonstrate the negative mental health consequences of the covid-19 restrictions for people with dementia. Our findings echo a small body of the existing literature on this topic. A study from Spain noted increases in levels of agitation, apathy, and aberrant motor behaviour five weeks into lockdown in outpatients with mild cognitive impairment and Alzheimer's disease (N=40), but no increase in psychotic symptoms.[27] A cross-sectional study from Italy (N=139) describes exacerbation of psychotic symptoms in a small percentage of subjects with subjective cognitive decline, mild cognitive impairment, and dementia.[28] This study, in part, utilised self-assessments, that may have led to underreporting of delusions and hallucinations. Even though other studies are equivocal on whether psychosis worsened,[8, 9] UK registry data indicate higher antipsychotic prescription rates to people with dementia during the pandemic, and the authors speculate that this increase may be the result of worsened agitation and psychosis.[29] Meanwhile, our study revealed no associations between psychotropic drugs and psychosis, likely given that very few patients used antipsychotics before the pandemic, in addition to the lack of real-time prescription data throughout the outbreak. Because this is a nascent area of research, discrepancies may be attributed to heterogeneity in design, as well as dementia severity and aetiology.

Early findings suggest that older adults at group level are more resilient to the mental health effects of the pandemic than younger ones.[11] Nonetheless, our study adds to the cross-sectional reports calling attention to deteriorating depressive symptoms among people with dementia.[8-10] Anxiolytics and hypnotics/sedatives were used on-demand in our sample. These drugs are known to temporarily alleviate some of the symptoms assessed by the CSDD, such as anxiety, irritability and agitation. However, in line with national guidelines, we rather recommend that antidepressants are considered if severe symptoms persist.[30]

Our study confirms the World Health Organisation's concerns that the pandemic would negatively impact the mental health of people with cognitive impairments.[5] Even though way of life varies globally, the policies implemented in response to covid-19 are likely equally disruptive to the environment of home-dwelling people with dementia across nations.[3] We, therefore, argue that our findings are generalisable to other countries. Furthermore, they emphasise that nonpharmacological approaches still should be the first-line treatment to avoid BPSD deterioration regardless of context.

### Unanswered questions and future research

Future research should explore the long-term impact of the covid-19 restrictions on BPSD, and whether moderations or service innovations can mitigate worsening. Less than 5% of trials on covid-19 involve behavioural and mental health interventions,[31] emphasising the need for knowledge to adapt restrictions and navigate the unforeseeable consequences of the current, and future, pandemics.

## STATEMENTS

### Contributor and guarantor information

BSH was primary investigator. MHG, BSH, MV, and LIB designed and planned the study. MHG, MV, and LIB collected data. MHG did the data analysis, supervised by JM. MHG and LIB wrote the first draft of the manuscript. MHG, BSH, IVV, JM, MV, MN, and LIB were actively involved in interpreting the results, revising the manuscript, and approving the final version. LIB is responsible for the overall content as guarantor. The corresponding author attests that all listed authors meet the authorship criteria and that no others fulfilling authorship criteria are omitted.

### Acknowledgements

Renira Angeles (postdoctoral fellow, NORCE) and Nathalie Puaschitz (postdoctoral fellow, Western Norway University of Applied Sciences) contributed to data collection. Rune Samdal secured public and patient involvement. The motivation and willingness of dyads and municipal personnel in Bergen, Bærum, and Kristiansand made this study possible.

### Transparency statement

LIB (the manuscripts guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study; that no important aspects of the study have been omitted; and that any discrepancies from the study as originally planned (and, if relevant, registered).

### Funding statement

This work was supported by the Research Council of Norway (grant number 273581). The Norwegian Government and the G.C. Rieber Foundation supports the Centre for Elderly and Nursing Home Medicine, University of Bergen, organising the conduction of

LIVE@Home.Path and PAN.DEM. The research was designed, conducted, analysed, interpreted, and written by the authors independently of the funding sources. All authors had access to the data in the study and can take responsibility for the integrity of the data and the accuracy of data analysis.

**Competing interests declaration**

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: MHG, MV, JM, and LIB had financial support from the Research Council of Norway (grant number 273581), for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; IVV reports receiving honorarium as editor of the American Journal of Geriatric Psychiatry.

**Data sharing**

Relevant anonymised data are available at reasonable request. Data are fully available to collaborators and affiliated researchers.

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**Dissemination declaration**

The results of this study will be disseminated to relevant user organisations (Norwegian Health Organisation), participants, affiliated health care personnel and external healthcare workers, as well as health authorities.

**FIGURE LEGENDS**

**Figure 1: The parent trial, LIVE@Home.Path, including PAN.DEM.** The covid-19 restrictions replaced trial protocol from 12 Mar. until eased on 15 May 2020. None of the dyads (person with dementia and informal carer, n) received the intervention whilst the PAN.DEM interviews were conducted (20 Apr. to 15 May 2020). **Panel a: Timeline.** Vertical lines indicate assessments. The shaded parts illustrate the covid-19 restrictions, postponing the LIVE-Intervention (Learning, Innovation, Volunteers, and Empowerment) for the dyads of

Group 2. **Panel b: Flowchart.** This study includes the dyads of PAN.DEM completing the pre-pandemic assessment before the covid-19 restrictions was implemented on 12 Mar. 2020. *Parent trial attrition: rate within assumptions of loss to follow-up.

**Figure 2: Change in behavioural and psychological symptoms in n (%) persons with dementia from the pre-pandemic to the pandemic assessment.** n: 104. Pre-pandemic: Six-month assessment of parent trial (12 Dec. 2019 to 11 Mar. 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). Neuropsychiatric Inventory, subsyndrome score: psychosis (delusions and hallucinations), hyperactive behaviour (agitation, euphoria, irritation, disinhibition, aberrant motor behaviour), mood (depression, apathy, sleep disturbances, and appetite changes). Cornell Scale for Depression in Dementia, total score.

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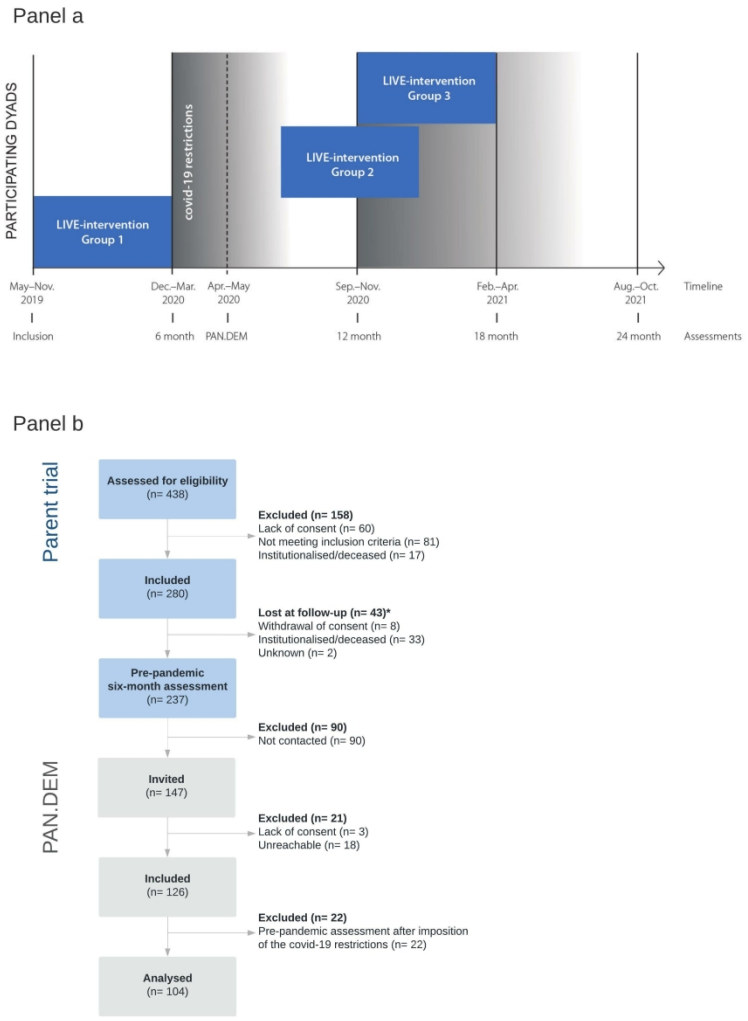


**Figure 1: The parent trial, LIVE@Home.Path, including PAN.DEM.** The covid-19 restrictions replaced trial protocol from 12 Mar. until eased on 15 May 2020. None of the dyads (person with dementia and informal carer, n) received the intervention whilst the PAN.DEM interviews were conducted (20 Apr. to 15 May 2020). **Panel a: Timeline.** Vertical lines indicate assessments. The shaded parts illustrate the covid-19 restrictions, postponing the LIVE-Intervention (Learning, Innovation, Volunteers, and Empowerment) for the dyads of Group 2. **Panel b: Flowchart.** This study includes the dyads of PAN.DEM completing the pre-pandemic assessment before the covid-19 restrictions was implemented on 12 Mar. 2020. *Parent trial attrition: rate within assumptions of loss to follow-up.

266x383mm (300 x 300 DPI)

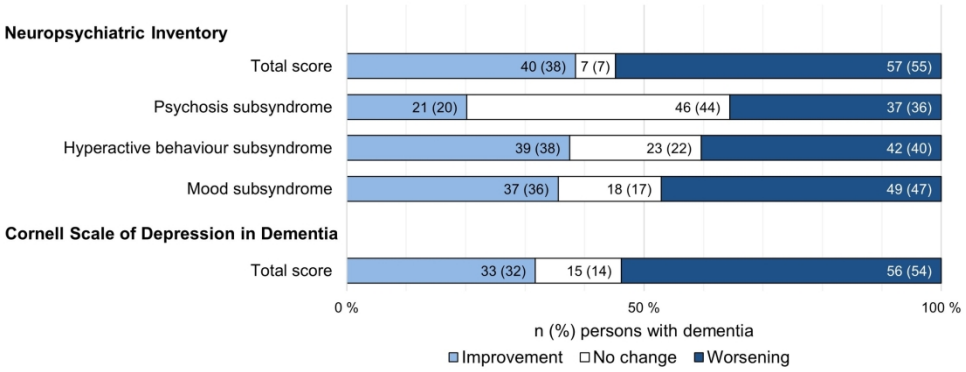


**Figure 2: Change in behavioural and psychological symptoms in n (%) persons with dementia from the pre-pandemic to the pandemic assessment.** n: 104. Pre-pandemic: Six-month assessment of parent trial (12 Dec. 2019 to 11 Mar. 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). Neuropsychiatric Inventory, subsyndrome score: psychosis (delusions and hallucinations), hyperactive behaviour (agitation, euphoria, irritation, disinhibition, aberrant motor behaviour), mood (depression, apathy, sleep disturbances, and appetite changes). Cornell Scale for Depression in Dementia, total score.

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Supplementary table A: Factors associated with worsening in behavioural and psychological symptoms of dementia from the pre-pandemic to the pandemic assessment.

| | NPI-12 total score | | | | NPI-12 psychosis subsyndrome | | | | CSDD total score | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Covariates | OR | 95% CI lower | 95% CI upper | P | OR | 95% CI lower | 95% CI upper | P | OR | 95% CI lower | 95% CI upper | P |
| *Pre-pandemic characteristics* | | | | | | | | | | | | |
| *Person with dementia* | | | | | | | | | | | | |
| Age | 1.01 | 0.92 | 1.11 | 0.79 | 0.91 | 0.82 | 1.01 | 0.16 | 1.09 | 0.97 | 1.22 | 0.16 |
| Female | 0.51 | 0.13 | 1.98 | 0.34 | 0.36 | 0.09 | 1.52 | 0.09 | 0.19 | 0.03 | 1.31 | 0.09 |
| Living alone | 0.20 | 0.04 | 1.01 | 0.05 | 2.69 | 0.41 | 17.80 | 0.31 | 0.55 | 0.07 | 4.18 | 0.57 |
| Alzheimer's Disease [a] | 0.18 | 0.05 | 0.63 | 0.01* | 0.84 | 0.23 | 3.08 | 0.79 | 0.21 | 0.05 | 0.85 | 0.03* |
| MMSE [b] | 1.19 | 1.01 | 1.40 | 0.04* | 0.97 | 0.82 | 1.14 | 0.68 | 0.96 | 0.80 | 1.15 | 0.65 |
| FAST [c] | 0.98 | 0.45 | 2.16 | 0.97 | 2.59 | 1.07 | 6.27 | 0.04* | 4.96 | 1.57 | 15.65 | 0.01* |
| IADL [d] | 0.96 | 0.80 | 1.15 | 0.64 | 1.19 | 0.98 | 1.45 | 0.08 | 0.84 | 0.67 | 1.07 | 0.16 |
| PSMS [e] | 1.00 | 0.79 | 1.28 | 0.99 | 0.68 | 0.51 | 0.91 | 0.01* | 0.99 | 0.76 | 1.29 | 0.96 |
| GMHR [f] | 0.91 | 0.36 | 2.32 | 0.84 | 2.06 | 0.72 | 5.88 | 0.18 | 0.84 | 0.28 | 2.50 | 0.76 |
| Psychotropic drugs [g] | | | | | | | | | | | | |
| Regularly | 1.16 | 0.54 | 2.48 | 0.71 | 0.67 | 0.31 | 1.47 | 0.32 | 1.11 | 0.49 | 2.53 | 0.80 |
| On-demand | 0.35 | 0.09 | 1.46 | 0.15 | 2.95 | 0.69 | 12.66 | 0.15 | 0.16 | 0.03 | 0.75 | 0.02* |
| *Carer* | | | | | | | | | | | | |
| Age | 0.97 | 0.92 | 1.03 | 0.40 | 1.04 | 0.98 | 1.12 | 0.21 | 0.99 | 0.93 | 1.06 | 0.87 |
| Female | 1.81 | 0.50 | 6.49 | 0.36 | 0.70 | 0.18 | 2.80 | 0.62 | 0.82 | 0.16 | 4.27 | 0.82 |
| | | | | | | | | | | | | |
| *Pandemic* | | | | | | | | | | | | |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| *characteristics, person with dementia* | | | | | | | | | | | | |
| Insight to the covid-19 situation [h] | | | | | | | | | | | | |
| Partial | 0.61 | 0.10 | 3.69 | 0.60 | 9.57 | 1.14 | 80.71 | 0.04* | 0.67 | 0.10 | 4.44 | 0.68 |
| Sufficient | 1.14 | 0.15 | 8.82 | 0.90 | 3.69 | 0.33 | 40.93 | 0.29 | 2.70 | 0.26 | 28.27 | 0.41 |
| Contact with the carer [i] | | | | | | | | | | | | |
| Reduced | 1.88 | 0.48 | 7.44 | 0.37 | 4.45 | 1.01 | 19.71 | 0.049* | 1.40 | 0.27 | 7.27 | 0.69 |
| Increased | 2.41 | 0.61 | 9.49 | 0.21 | 3.21 | 0.71 | 14.55 | 0.13 | 0.30 | 0.07 | 1.23 | 0.10 |
| Ceased volunteering services | 0.30 | 0.04 | 2.24 | 0.24 | 0.20 | 0.02 | 2.11 | 0.18 | 0.59 | 0.04 | 7.91 | 0.69 |
| Change in health care services | 0.48 | 0.13 | 1.78 | 0.28 | 0.48 | 0.11 | 2.08 | 0.33 | 1.16 | 0.28 | 4.83 | 0.84 |
| Postponed or averted contacts with health care professionals | 3.96 | 1.05 | 14.95 | 0.04* | 1.55 | 0.45 | 5.42 | 0.49 | 3.37 | 0.70 | 16.08 | 0.13 |

Table legend:

n: 89 dyads (person with dementia and carer). Pre-pandemic: Six-month assessment of parent trial (12 Dec. 2019 to 11 Mar. 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). NPI-12: Neuropsychiatric Inventory, twelve item version; with psychosis subsyndrome constituting delusions and hallucinations (psychotic symptoms). CSDD: Cornell Scale of Depression in Dementia (depressive symptoms). Change dichotomised into worsening/not worsening. OR: Odds Ratio, explored by multiple logistic regression, estimates adjusted for all other factors in the models. 95%CI: 95% Confidence Interval. *P*: two-tailed, * indicates *P* value <0.05.

[a]: Alzheimer's disease, reference: all other dementia aetiologies.

[b]: MMSE, Mini-Mental Status Examination, at inclusion, range 0-30, higher scores indicate better cognition, reference: 30

[c]: FAST, Functional Assessment Scaling, at inclusion, range 1-7, lower scores indicate better functioning, reference: 1

[d]: IADL, Instrumental Activities of Daily Living Scale, range 8-31, lower scores indicate better functioning, reference: 8

[e]: PSMS, Physical Self-Maintenance Scale, range 6-30, lower scores indicate better functioning, reference 6.

[f]: GMHR, General Medical Health Rating Scale, range 1-4, lower score indicate higher comorbidity burden, reference 4.

[g]: Number of psychotropic drugs according to the Anatomical Therapeutic Chemical Index: antipsychotics (N05A), anxiolytics (N05B), hypnotics/sedatives (N05C), antidepressants (N06A), and anti-dementia drugs (N06D), reference: 0.

[h]: Degree of insight into the covid-19 situation as perceived by the carer, reference: no insight.

[i]: Change in contact with the carer, reference: no change.

Supplementary table B: Post-hoc analysis of associations between worsening in behavioural and psychological symptoms (from the pre-pandemic to the pandemic assessment) and pre-pandemic traits for the 104 persons with dementia.

| | mean (SD) | P |
|---|---|---|
| NPI-12 total score | | |
| Use of psychotropic drugs (N05A, N05B, N05C, N06A, N06D) | | |
| Yes | 0.58 (0.50) | 0.36 |
| No | 0.47 (0.51) | |
| Use of antidementia drugs (N06D) | | |
| Yes | 0.58 (0.50) | 0.85 |
| No | 0.48 (0.50) | |
| Receiving the LIVE-intervention[#] | | |
| Yes | 0.57 (0.51) | 0.81 |
| No | 0.54 (0.40) | |
| NPI-12 psychosis subsyndrome | | |
| Use of antipsychotic drugs (N05A) | | |
| Yes | 0.33 (0.52) | 0.92 |
| No | 0.36 (0.48) | |
| Receiving the LIVE-intervention[#] | | |
| Yes | 0.29 (0.46) | 0.45 |
| No | 0.37 (0.49) | |
| CSDD total score | | |
| Use of antidepressant drugs (N06A) | | |
| Yes | 0.63 (0.50) | 0.88 |
| No | 0.61 (0.49) | |
| Receiving the LIVE-intervention[#] | | |
| Yes | 0.62 (0.50) | 0.97 |
| No | 0.61 (0.49) | |

Table legend:

Pre-pandemic: Six-month assessment of the parent trial (12 Dec 2019 to 11 Mar 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 15 2020). SD: standard deviation. P: P values for difference between groups by unequal variances t-test, * indicates two-tailed P<.05. NPI-12: Neuropsychiatric Inventory, twelve item version: with psychosis subsyndrome constituting delusions and hallucinations. CSDD: Cornell Scale of Depression in Dementia. Change dichotomised into worsening/not worsening. Drugs classified by the Anatomical Therapeutic Chemical Index. [#]21 (20%) received the LIVE-intervention: Multicomponent intervention of the parent trial comprising Learning, Innovation, Volunteers, and Empowerment.

Supplementary table C: Comparison of PAN.DEM study sample to those not included yet still in parent trial.

| | Pre-pandemic six-month assessment of parent trial (n=237) | | | | |
|---|---|---|---|---|---|
| | PAN.DEM study sample (n=104) | | Not included in PAN.DEM study sample (n=133) | | P |
| | n (%) | median [IQR] | n (%) | median [IQR] | |
| *Person with dementia* | | | | | |
| Age, mean (SD) | | 82 (7) | | 83 (7) | 0.38 |
| Gender, Female | 63 (61) | | 86 (65) | | 0.47 |
| Residency | | | | | 0.93 |
| Living alone | 46 (44) | | 54 (41) | | |
| Coresiding with the reporting carer | 46 (44) | | 59 (44) | | |
| Coresiding with someone else than the carer | 12 (12) | | 16 (12) | | |
| Dementia aetiology by ICD-10 | | | | | 0.003* |
| Alzheimer's Disease | 45 (43) | | 43 (32) | | |
| Vascular Dementia | 6 (6) | | 2 (2) | | |
| Dementia in other diseases classified elsewhere | 10 (10) | | 4 (3) | | |
| Unspecified Dementia | 43 (41) | | 82 (62) | | |
| MMSE, range 0-30 | | 21 [18, 24] | | 21 [18, 23] | 0.83 |
| FAST, range 1-7 | | 4 [4, 4] | | 4 [4, 5] | 0.15 |
| GMHR, range 1-4 | | 3 [2, 3] | | 3 [3, 4] | <0.001* |
| PSMS, range 6-30 | | 11 [9, 14] | | 11 [9, 14] | 0.40 |
| IADL, range 8-31 | | 22 [18, 27] | | 22 [16, 27] | 0.65 |
| Drugs in general, total number | | 6 [4, 8] | | 4 [2, 7] | 0.002* |
| Psychotropic drugs | | | | | |
| Total number | | 1 [0, 1] | | 1 [0, 2] | 0.02* |
| Regularly | | 1 [0, 1] | | 1 [0, 1] | 0.07 |
| On-demand | | 0 [0, 0] | | 0 [0, 0] | 0.06 |
| Health care services | | | | | |

| | | | |
|---|---|---|---|
| Daily Home Nursing | 52 (50) | 46 (35) | 0.02* |
| Weekly Day Care | 29 (28) | 37 (28) | 0.99 |
| Respite Care (In-Home and Out-of-Home) | 2 (2) | 9 (7) | 0.08 |
| Volunteering services | 8 (8) | 22 (17) | 0.14 |
| *Behavioural and psychological symptoms of dementia* | | | |
| NPI-12 total score, range 0-144 | 16 [4.5, 29] | 12.5 [4, 28] | 0.74 |
| CSDD total score, range 0-38 | 5 [3, 9] | 6 [2, 12] | 0.32 |
| *Carer* | | | |
| Age, mean (SD) | 65 (12) | 68 (12) | 0.17 |
| Gender, female | 68 (65) | 83 (62) | 0.64 |
| Kinship to the person with dementia | | | 0.06 |
| Spouse | 44 (42) | 58 (44) | |
| Child | 58 (56) | 63 (47) | |
| Others | 2 (2) | 12 (9) | |

Table legend:

n: dyads (person with dementia and carer). IQR: Interquartile range. SD: standard deviation. P: P values for difference between groups by two sample t-test, Wilcoxon-Mann-Whitney test, or Pearson chi-squared test, * indicates P<.05 ICD-10: International Statistical Classification of Diseases and Related Health Problems. MMSE: Mini-Mental Status Examination, at inclusion. FAST, Functional Assessment Scaling, at inclusion. GMHR: General Medical Health Rating Scale. PSMS: Physical Self-Maintenance Scale. IADL: Instrumental Activities of Daily Living Scale. NPI-12: Neuropsychiatric Inventory. CSDD: Cornell Scale for Depression in Dementia. Drugs were classified by the Anatomical Therapeutic Chemical Index; antipsychotics, anxiolytics, hypnotics/sedatives, antidepressants, and anti-dementia drugs constituted psychotropic drugs.

# The PAN.DEM assessment

Respondents: informal carers in the LIVE@Home.Path trial

1 **Date of birth:** mm.dd.yyyy

2 **Are you temporarily laid off due to the covid-19 restrictions?**

- ☐ Yes
- ☐ No
- ☐ Not applicable

3 **During the last month, have you been quarantined due to covid-19?**

- ☐ Yes
- ☐ No

**If yes, please specify:**

_____

4 **Does the person with dementia have insight into the covid-19 situation?**

- ☐ To no degree
- ☐ Partial
- ☐ Sufficient

5 **To what degree are you concerned that the person with dementia will be infected with covid-19?**

Tick a number on the scale from 0-10 (0=not at all; 10=as much as possible):

0 1 2 3 4 5 6 7 8 9 10

6 **To what degree are you concerned that you yourself will be infected with covid-19?**

Tick a number on the scale from 0-10 (0=not at all; 10=as much as possible)

0 1 2 3 4 5 6 7 8 9 10

7 **To what degree are you concerned that you yourself will be infected with covid-19?**

Tick a number on the scale from 0-10: (0=not at all; 10=as much as possible):

0 1 2 3 4 5 6 7 8 9 10

8 **To what degree are your concern for own infection sourced from your responsibilities as carer?**

Tick a number on the scale from 0-10:(0=not at all; 10=as much as possible):

0 1 2 3 4 5 6 7 8 9 10

9 **As a response to the covid-19 pandemic, did you discuss advanced care planning with the person with dementia?** If yes, please specify below.

_____

10 **Did the covid-19 restrictions have any consequences for the healthcare services provided by the municipality for the person with dementia** (e.g. home nursing services, activity groups, day care centre, respite care).

☐ Yes
☐ No

**If yes, specify per Resource Utilization in Dementia Version 4 section A2.2.5** [1 2]

11 **Have you avoided or postponed contacts with health care professionals due to the COVID-19 pandemic and the restrictions?**

☐ Yes
☐ No

**If yes, please specify:**

_____

12 **Informal care time assessed by Resource Utilization in Dementia Version 4 section B1.2** [1 2]

13 **Has the food habits and appetite of the person with dementia changed under to the covid-19 restrictions?**

☐ Yes
☐ No

**If yes, please specify:** Tick one or several items.

☐ Eats/drinks less
☐ Loss of appetite
☐ Eats more
☐ Eats mote unhealthy food
☐ Has stopped preparing food him/herself
☐ Heats prepared food
☐ Is unable to maintain diet without help from informal or formal carers

14 **Neuropsychiatric inventory (12 item version)** [3]

15 **Cornell Scale of Depression in Dementia** [4]

16 **Has the pandemic had any consequences for services provided by volunteers?**

☐ Yes
☐ No

**If yes, specify as applicable:**

_____

17 **Has the covid-19 restrictions increased your interest in assistive technology?**

☐ Yes
☐ No

**If yes, specify as applicable** including complaint/need, type of technology, if acquired, including privately financed or municipally funded:

_____

18 **Compared to pre-pandemic levels, what sort of contact have you had with the person with dementia?** Tick one or several items.

- ☐ Unchanged
- ☐ Increased
- ☐ Reduced
- ☐ No contact at all
- ☐ More digital contact

19 **Have you implemented measures and restrictions to prevent transmission of covid-19 to the person with dementia?** Please specify as applicable:

_____

20 **Compared to immediately before the pandemic, how would you rank your own total situation as a carer?** [5]

Tick a number from -5 (much worse) to 5 (much better), via 0 (no change).

-5 -4 -3 -2 -1 0 1 2 3 4 5

21 **Do you have any additional comments?** Please specify as applicable:

_____



## References


1. Wimo A, Gustavsson A, Jonsson L, et al. Application of Resource Utilization in Dementia (RUD) instrument in a global setting. *Alzheimers Dement* 2013;9(4):429-35 e17. doi: 10.1016/j.jalz.2012.06.008 [published Online First: 2012/11/13]
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STROBE Statement—checklist of items that should be included in reports of observational studies

| | Item No | Recommendation | Page in manuscript |
|---|---|---|---|
| **Title and abstract** | 1 | (*a*) Indicate the study's design with a commonly used term in the title or the abstract | Page 1 and 2 |
| | | (*b*) Provide in the abstract an informative and balanced summary of what was done and what was found | Page 2 |
| **Introduction** | | | |
| Background/rationale | 2 | Explain the scientific background and rationale for the investigation being reported | Page 3 and 4 |
| Objectives | 3 | State specific objectives, including any prespecified hypotheses | Page 4 |
| **Methods** | | | |
| Study design | 4 | Present key elements of study design early in the paper | Page 4 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | Page 4 |
| Participants | 6 | (*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up<br>*Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls<br>*Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants | Page 4 and figure 1 |
| | | (*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed<br>*Case-control study*—For matched studies, give matching criteria and the number of controls per case | Not applicable |
| Variables | 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | Page 5 |
| Data sources/ measurement | 8* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | Page 5 |
| Bias | 9 | Describe any efforts to address potential sources of bias | Page 4 and 11 |
| Study size | 10 | Explain how the study size was arrived at | Page 4 and 11 |
| Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why | Page 6 |
| Statistical methods | 12 | (*a*) Describe all statistical methods, including those used to control for confounding | Page 6 |
| | | (*b*) Describe any methods used to examine subgroups and interactions | Page 6 and 11 |

| | | | |
|---|---|---|---|
| | | (*c*) Explain how missing data were addressed | Page 6 |
| | | (*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed<br>*Case-control study*—If applicable, explain how matching of cases and controls was addressed<br>*Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy | Figure 1, page 11 |
| | | (*e*) Describe any sensitivity analyses | Page 12 |
| **Results** | | | |
| Participants | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed | Page 6 and figure 1 |
| | | (b) Give reasons for non-participation at each stage | Figure 1 |
| | | (c) Consider use of a flow diagram | Figure 1 |
| Descriptive data | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders | Page 7, table 1, table 2 |
| | | (b) Indicate number of participants with missing data for each variable of interest | Page 6 |
| | | (c) *Cohort study*—Summarise follow-up time (eg, average and total amount) | Page 6 |
| Outcome data | 15* | *Cohort study*—Report numbers of outcome events or summary measures over time | Page 9, table 3 |
| | | *Case-control study*—Report numbers in each exposure category, or summary measures of exposure | |
| | | *Cross-sectional study*—Report numbers of outcome events or summary measures | |
| Main results | 16 | (*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | Page 9 and 10, table 3 and supplementary table A |
| | | (*b*) Report category boundaries when continuous variables were categorized | Page 5 |
| | | (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | |
| Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses | Page 11 |
| **Discussion** | | | |
| Key results | 18 | Summarise key results with reference to study objectives | Page 11 |
| Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | Page 11 and 12 |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | Page 11-13 |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results | Page 11 and 13 |

| **Other information** | | | |
|---|---|---|---|
| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | Page 13 |

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

# The impact of covid-19 restrictions on behavioural and psychological symptoms in home-dwelling people with dementia: a prospective cohort study (PAN.DEM)

| | |
|---|---|
| Journal: | *BMJ Open* |
| Manuscript ID | bmjopen-2021-050628.R2 |
| Article Type: | Original research |
| Date Submitted by the Author: | 30-Nov-2021 |
| Complete List of Authors: | Gedde, Marie; University of Bergen, Department of Global Public Health and Primary Care; Haraldsplass Diakonale Sykehus AS,<br>Husebo, Bettina; University of Bergen, Department of Global Public Health and Primary Care; Bergen Municipality<br>Vahia, Ipsit ; McLean Hospital; Harvard Medical School<br>Mannseth, Janne ; University of Bergen, Department of Global Public Health Primary Care, Faculty of Medicine, University of Bergen, Bergen, Norway<br>Vislapuu, Maarja; University of Bergen, Department of Global Public Health and Primary Care<br>Naik, Mala; Haraldsplass Diakonale Sykehus AS, Medical Clinic; University of Bergen, Department of Clinical Science<br>Berge, Line ; NKS Olaviken Gerontopsychiatric Hospital; University of Bergen, Department of Global Public Health Primary Care, Faculty of Medicine, University of Bergen, Bergen, Norway |
| Primary Subject Heading: | Neurology |
| Secondary Subject Heading: | Health policy, Geriatric medicine, Mental health, General practice / Family practice |
| Keywords: | Dementia < NEUROLOGY, COVID-19, Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Old age psychiatry < PSYCHIATRY, PRIMARY CARE |
| | |

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# The impact of covid-19 restrictions on behavioural and psychological symptoms in home-dwelling people with dementia: a prospective cohort study (PAN.DEM)

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Word count: 3080

## ABSTRACT

**Objectives**: To investigate the impact of the covid-19 restrictions on behavioural and psychological symptoms of dementia (BPSD).

**Design**: Prospective cohort study (PAN.DEM) nested within the halted parent trial (LIVE@Home.Path).

**Setting**: Households in Norway immediate before and six to nine weeks into the covid-19 restrictions.

**Participants**: 104 dyads (persons with mild to moderate dementia aged ≥65 and their informal carers) completed both pre- and pandemic assessments, amongst 237 in the parent trial. Mini-Mental Status Examination score 15-26 or Functional Assessment Staging score 3-7 covered dementia severity.

**Main outcome measures**: Neuropsychiatric Inventory (NPI-12) total (range 0-144), psychosis (range 0-24), hyperactive behaviour (range 0-60), and mood subsyndrome (range 0-48) scores; Cornell Scale for Depression in Dementia (CSDD) total score (range 0-38).

**Results**: We found an overall increase in BPSD by NPI-12 total score comparing pre-pandemic to pandemic levels (median 16 interquartile range [4.5, 29] to 20 [7, 32.5], P=0.03) over a mean of 86 days (standard deviation 19). NPI-12 total score worsened in 57 (55%) of people with dementia and was associated with postponed or averted contacts with health care professionals (logistic regression, odds ratio 3.96, 95% confidence interval 1.05 to 14.95). Psychosis subsyndrome levels increased (0 [0, 3] to 0.5 [0, 6], P=0.01) in 37 (36%) persons; this worsening was associated with partial insight (9.57, 1.14 to 80.71) and reduced informal carer contact (4.45, 1.01 to 19.71). Moreover, depressive symptoms increased as assessed by CSDD total score (5 [3, 9] to 7 [4, 12], P=0.01) and worsened for 56 (54%), which was inversely associated with psychotropic drugs on-demand (0.16, 0.03 to 0.75).

**Conclusions**: BPSD worsened during the first months of the covid-19 restrictions, most pronounced for psychosis and depression. These BPSD exacerbations have implications for pandemic policies, emphasising that restrictions must balance covid-19 morbidity and mortality against dementia deterioration.

**Registration**: ClinicalTrials.gov; NCT04043364.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- This is the first prospective cohort study investigating the impact of the covid-19 restrictions on behavioural and psychological symptoms of dementia (BPSD).
- The same informal carers reported BPSD for each home-dwelling person with dementia both before and during the pandemic scenario using validated, well-established instruments.
- The covid-19 restrictions left some informal carers with less basis of observation, as 28% reported reduced contact with the person with dementia.
- Our study captures the impact of the initial phase of the outbreak in Norway and does not describe the long-term impact of the covid-19 restrictions on BPSD.

## INTRODUCTION

Dementia is among the most critical risk factors for covid-19 mortality.[1] In England and Wales alone, 12,869 people with dementia have died, accounting for 26% of the covid-19 death toll.[2] Until vaccination is widely available globally, hygiene and physical distancing interventions will remain cornerstones of protecting vulnerable populations.[3] The subsequent restrictions have been disrupting for home-dwelling people with dementia as private homes were not accessible to family members and volunteers, day care centres closed, and home nursing services were restricted to those most in need. As a result, people with dementia living in the community are not only at risk from covid-19 morbidity and mortality; they are also threatened from unforeseen effects of the restrictions.[4, 5]

Behavioural and psychological symptoms of dementia (BPSD) cover a wide range of clinical presentation including depression, anxiety, agitation, and psychosis. Longitudinally, persistent BPSD may be found in up to 80% of people with dementia.[6] BPSD are best managed with structured, non-pharmacological interventions, placing psychotropic drugs as secondary treatment options.[7] Preliminary evidence indicates that BPSD may be exacerbated under the covid-19 restrictions. Eight weeks into the Argentinian quarantine, informal carers reported worsening of anxiety, insomnia, and depression among persons at different stages of Alzheimer's and related dementias living at home (N=119).[8] In another study, family carers stated worsening BPSD in 60% of Italian outpatients with various stages and aetiologies of dementia one month into the pandemic (N=4,913).[9] This study also found that 28% required changes in psychotropic medication to address irritability, apathy, agitation, and depression. Further, nursing home patients separated from the outside world in France with mild Alzheimer's disease reported increased anxiety and depression when asked to evaluate their own experience of the pandemic retrospectively (N=58).[10]

However, all these studies are cross-sectional and thus far, there is a dearth of longitudinal data tracking changes in BPSD during covid-19 by comparing pre-pandemic to pandemic rates.[11] In this study, we aim to address this significant gap in the literature using data from the prospective PAN.DEM study.[12] This study is nested within the ongoing LIVE@Home.Path trial[13] and was launched by our team to investigate the impact of the covid-19 restrictions (implemented in Norway on 12 Mar. 2020) on home-dwelling people with dementia. Here we present comparisons of pre-pandemic and pandemic BPSD, and explore factors associated with worsening BPSD.

## METHODS

### Study design

This is a prospective cohort study comparing the pre-pandemic assessment of BPSD of the parent trial, LIVE@Home.Path, to the PAN.DEM assessment.

### Setting

The parent trial is a stepped-wedge randomised controlled trial.[13] It compares the cost-effectiveness in resource utilisation of a six-month multicomponent intervention comprising Learning, Innovation, Volunteers, and Empowerment (LIVE) to usual conditions for dyads of home-dwelling people with dementia and their informal carers. Trained data collectors blindly assessed all dyads in direct conversation every six months for two years (2019 to 2021). The pre-pandemic six-month assessment was close to complete when the covid-19 restrictions replaced trial protocol (figure 1, panel a). Physical distancing (i.e., restrictions on gatherings, public transport closure, stay at home-regulations, and limitations on movement) formed the basis for the restrictions,[3] which implied that health care was limited to those most in need.[12] In response, we developed the semi-structured PANdemic in DEMentia (PAN.DEM) telephone interview for informal carers to capture if, and how, dyads were affected by the outbreak (supplementary file). This assessment included selected instruments from the parent trial in addition to questions regarding the pandemic. We consecutively invited as many dyads as possible from the parent trial to complete the PAN.DEM assessment from week six of restrictions until eased the ninth week (20 Apr. to 15 May 2020). Potential respondents were considered unreachable when no response was given to two calls and a text message.

### Participants

Dyads were eligible for inclusion in the parent trial if the persons with dementia were: ≥65 years, diagnosed with dementia (with Mini-Mental Status Examination (MMSE) score 15-26 or Functional Assessment Staging Test (FAST) score 3-7);[14, 15] home-dwelling in one of three Norwegian municipalities; and had weekly face-to-face contact with the informal carer.

**Measurements**

The primary outcome was change in BPSD between the pre-pandemic and pandemic assessments. We administered two informal carer-rated scales at both time points. 1) The Neuropsychiatric Inventory (NPI-12) assesses frequency and severity of delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibitions, irritability, aberrant motorial behaviour, sleep disturbances, and appetite changes over the four preceding weeks.[16] Each of these twelve domains is scored from 0 (no symptoms) to 12 (very severe symptoms), a score ≥4 is regarded a BPSD with symptom load of clinical relevance.[6] These domains are further aggregated to generate subsyndrome scores for psychosis comprised of delusions and hallucinations (0-24), hyperactive behaviour comprised of agitation, euphoria, irritation, disinhibition, aberrant motor behaviour (0-60), mood comprised of depression, apathy, sleep disturbances, and appetite changes (0-48), and finally, a total NPI-12 score (0-144).[17] 2) The Cornell Scale for Depression in Dementia (CSDD) assesses nineteen items of depressive symptoms during the prior week, each rated from 'absent' to 'severe' (0-2), or 'symptoms not possible to evaluate' (missing).[18] Adding item scores generate the CSDD total score (0-38).[18] A CSDD total score ≥8 indicates depression of clinical relevance.[19] The Norwegian versions of NPI-12 and CSDD have robust psychometric properties.[16, 18-20]

In addition to BPSD, we collected the following data at the pre-pandemic assessment: the persons with dementia's level of functioning in activities of daily living by Physical Self-Maintenance Scale (PSMS)[21] and Instrumental Activities of Daily Living Scale (IADL),[22] health by the General Medical Health Rating Scale (GMHR),[23] possible dementia aetiology following the International Classification of Diseases – 10th version (ICD-10),[24] and use of health care services and medications as specified by the dyads. Drugs catalogued in the Anatomical Therapeutic Chemical Index (ATC) administered in a set schedule were regarded 'regular', whereas all others were documented as 'on demand'.[25] Psychotropic drugs included antipsychotic (N05A), anxiolytic (N05B), hypnotic and sedative (N05C), antidepressant (N06A), and anti-dementia drugs (N06D) by ATC. Demographical data (age, gender, residency, kinship) were self-reported. We evaluated dementia severity in terms of cognition with MMSE and level of functioning with FAST at inclusion.[14, 15]

At the pandemic assessment, the informal carers were also asked to estimate the degree of insight presented by the person with dementia into the covid-19 situation and change in 1) contact with the informal carer, 2) volunteering services, and 3) municipal health care services (home nursing services, home help, day-care, and in-home and out-of-home respite care) due to the covid-19 restrictions.[12] Finally, informal carers stated if contacts with health care professionals were postponed or averted.

### Study size

This study includes all dyads in PAN.DEM completing the pre-pandemic assessment before the covid-19 restrictions were effectuated (figure 1, panel b).

*Figure 1 here*

### Statistical methods

Initially, we aggregated median and interquartile range (IQR), and calculated NPI-12 subsyndrome scores and total scores for NPI-12 and CSDD if >80% of the scales were answered. We used the Wilcoxon matched-pairs signed-rank test to assess change between the pre- and pandemic assessments. Next, we dichotomized those NPI-12 and CSDD sum scores that changed into worsening/not worsening and utilized multiple logistic regression analysis to explore factors associated. We included the following covariates for persons with dementia: age, gender, residency, dementia aetiology, MMSE, FAST, IADL, PSMS, GMHR, number of psychotropic drugs prescribed regularly and on-demand, and the covid-19 specific outcomes. We also included age and gender of the informal carers. Covariates were selected based on our expertise in research and clinical dementia care. The Akaike information criterion guided model selection. Selected models were then checked for multicollinearity, robustness, and goodness-of-fit by Pearson and Hosmer-Lemeshow test. FAST, IADL and PSMS showed moderate to strong positive correlation, but including all three covariates substantially improved the models. Missing data were handled with listwise deletion, with 14% missing any covariates. Calculations are expressed in odds ratio (OR) with 95% confidence intervals (95%CI), and P value. Reported P values are two-tailed, and $P<0.05$ was considered statistically significant. Descriptive statistics are presented by n (%), mean and standard deviation (SD), or median [IQR]. We used Stata/IC, release 16 (StataCorp LP, College Station, TX) for all analyses.

### Ethics

Dyads gave informed spoken and written consent for participation in the parent trial as described in the protocol.[13] Informal carers gave additional informed consent to PAN.DEM.[12] The Regional Committee for Medical and Health Research Ethics North Norway approved the parent trial (2019/385) and PAN.DEM (10861) before data was collected.

### Public and Patient Involvement

The conceptualisation, design, assessments, and conduct of the parent trial as well as PAN.DEM included close patient/informal carer and public involvement.[12, 13] A user-representative participated in the research group's weekly meetings. In PAN.DEM, he

consulted with the study team on priorities, length, and wording of the interview, and its revisions, with a special focus on the potential burden on informal carers.[12]

## RESULTS

Of the 280 dyads participating in the parent trial, 237 completed the pre-pandemic assessment from Dec. 2019 to Mar. 2020 (figure 1, panel b). This study includes 104 dyads recruited to PAN.DEM completing the pre-pandemic assessment before the covid-19 restrictions were effectuated 12 Mar. 2020. Mean time between assessments was 86 days (SD 19).

Table 1 shows that the mean age for people with dementia was 82 years (SD 7), 61% were women, 44% lived alone, and 50% received daily home-nursing services prior to the covid-19 restrictions. Alzheimer's disease constituted the most common dementia aetiology, while 6% had vascular dementia and 10% reported Lewy-body dementia or Parkinson's disease. Most people with dementia lacked insight into the covid-19 situation (table 2). The informal carers reported to have less contact with the person with dementia in 28% under the restrictions, and that contacts with health care professionals had been postponed or averted in 31%.

Table 1: Pre-pandemic characteristics for the 104 dyads (persons with dementia and informal carers, n).

| | *N=104* |
|---|---|
| *Person with dementia* | |
| Age, mean (SD) | 82 (7) |
| Female gender, n (%) | 63(61) |
| Residency | |
| Living alone, n (%) | 46 (44) |
| Coresiding with the reporting informal carer, n (%) | 46 (44) |
| Coresiding with someone else than the informal carer, n (%) | 12 (12) |
| Dementia aetiology | |
| Alzheimer's Disease, n (%) | 45 (43) |
| Vascular Dementia, n (%) | 6 (6) |
| Dementia in other diseases classified elsewhere, n (%) | 10 (10) |
| Unspecified Dementia, n (%) | 43 (41) |
| MMSE, range 0-30, median [IQR] | 21 [18, 24] |
| FAST, range 1-7, median [IQR] | 4 [4, 4] |
| GMHR, range 1-4, median [IQR] | 3 [2, 3] |
| PSMS, range 6-30, median [IQR] | 11 [9, 14] |
| IADL, range 8-31, median [IQR] | 22 [18, 27] |
| Drugs in general | |

| | |
|---|---|
| Total number, median [IQR] | 6 [4, 8] |
| Regularly, median [IQR] | 5 [3, 7] |
| Psychotropic drugs | |
| Total number, median [IQR] | 1 [0, 2] |
| Regularly, median [IQR] | 1 [0, 1] |
| Antipsychotic drugs (N05A), n (%) | 6 (6) |
| Anxiolytic drugs (N05B), n (%) | 3 (3) |
| Hypnotic/sedative drugs (N05C), n (%) | 10 (10) |
| Antidepressant drugs (N06A), n (%) | 19 (18) |
| Anti-dementia drugs (N06D), n (%) | 52 (50) |
| On-demand, median [IQR] | 0 [0, 0] |
| Antipsychotic drugs (N05A), n (%) | 0 (0) |
| Anxiolytic drugs (N05B), n (%) | 5 (5) |
| Hypnotic/sedative drugs (N05C), n (%) | 12 (12) |
| Antidepressant drugs (N06A), n (%) | 0 (0) |
| Anti-dementia drugs (N06D), n (%) | 0 (0) |
| Health care services | |
| Daily Home Nursing, n (%) | 52 (50) |
| Weekly Day Care, n (%) | 29 (28) |
| Respite Care (In-Home and Out-of-Home), n (%) | 2 (2) |
| Volunteering services, n (%) | 8 (8) |
| *Informal carer* | |
| Age, mean (SD), n (%) | 65 (12) |
| Female gender, n (%) | 68 (65) |
| Kinship to the person with dementia | |
| Spouse, n (%) | 44 (42) |
| Child, n (%) | 58 (56) |
| Others, n (%) | 2 (2) |

Table 1 legend:

Pre-pandemic: Six-month assessment of parent trial (12 Dec. 2019 to 11 Mar. 2020). IQR: interquartile range. SD: Standard deviation. ICD-10: International Statistical Classification of Diseases and Related Health Problems. MMSE: Mini-Mental Status Examination, at inclusion. FAST, Functional Assessment Staging, at inclusion. GMHR: General Medical Health Rating Scale. PSMS: Physical Self-Maintenance Scale. IADL: Instrumental Activities of Daily Living Scale. Drugs were classified by the Anatomical Therapeutic Chemical Index; antipsychotics, anxiolytics, hypnotics/sedatives, antidepressants, and anti-dementia drugs constituted psychotropic drugs.

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Table 2: Pandemic characteristics for the 104 persons with dementia (n) as perceived by their informal carers.

| | *N= 104* |
|---|---|
| Degree of insight | |
| Sufficient, n (%) | 34 (33) |
| Partial, n (%) | 54 (52) |
| To no degree, n (%) | 16 (15) |
| Change in contact with the informal carer# | |
| Reduced, n (%) | 29 (28) |
| No change, n (%) | 49 (47) |
| Increased, n (%) | 23 (22) |
| Ceased volunteering services#, n (%) | 8 (8) |
| Change in health care services#, n (%) | 42 (40) |
| Postponed or averted contacts with health care professionals#, n (%) | 32 (31) |

Table 2 legend:

Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). #Relative the pre-pandemic situation. Health care services provided by the municipality: home nursing services, home help, day-care, and respite care (In-Home and Out-of-Home).

From the pre- to the pandemic assessment, people with dementia experienced an increase in NPI-12 total score (16 [4.5, 29] to 20 [7, 32.5], P=0.03) and in numbers of BPSD with symptom load of clinical relevance (2 [0, 4] to 3 [1, 5], P<0.001) (table 3). Also, the NPI-12 score worsened for 55% (figure 2). We found an increase in the psychosis subsyndrome (0 [0, 3] to 0.5 [0, 6], P=0.01), with 36% experiencing more severe symptoms (figure 2). We also found an increase in depressive symptoms measured both by the NPI-12 depression domain (0 [0, 3] to 1 [0, 6], P=0.04) and CSDD total score (5 [3, 9] to 7 [4, 12], P=0.01, table 3). Additionally, the CSDD total score worsened for 54% (figure 2).

Table 3: Pre-pandemic compared to pandemic behavioural and psychological symptoms (BPSD) for the 104 persons with dementia (n).

| | Pre-pandemic | | | Pandemic | | | |
|---|---|---|---|---|---|---|---|
| | n (%) with symptom load of clinical relevance# | median | IQR | n (%) with symptom load of clinical relevance# | median | IQR | P |
| *Neuropsychiatric inventory (NPI-12)* | | | | | | | |
| Total score, range 0-144 | | 16 | [4.5, 29] | | 20 | [7, 32.5] | 0.03* |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Subsyndromes | | | | | | | |
| Psychosis, range 0-24 | | 0 | [0, 3] | | 0.5 | [0, 6] | 0.01* |
| Hyperactive behaviour, range 0-60 | | 5.5 | [0, 12] | | 4 | [0, 12] | 0.79 |
| Mood, range 0-48 | | 6 | [0, 12] | | 6.5 | [1, 12] | 0.21 |
| Domain scores, range 0-12 | | | | | | | |
| Delusions | 20 (19) | 0 | [0, 2] | 31 (30) | 0 | [0, 6] | 0.04* |
| Hallucinations | 8 (8) | 0 | [0, 0] | 16 (15) | 0 | [0, 0] | 0.23 |
| Agitation | 23 (22) | 0 | [0, 3] | 18 (17) | 0 | [0, 2] | 0.45 |
| Depression | 25 (24) | 0 | [0, 3] | 40 (38) | 1 | [0, 6] | 0.04* |
| Anxiety | 18 (17) | 0 | [0, 2] | 31 (30) | 0 | [0, 4] | 0.07 |
| Euphoria | 8 (8) | 0 | [0, 0] | 4 (4) | 0 | [0, 0] | 0.19 |
| Apathy | 35 (34) | 0 | [0, 4] | 30 (29) | 0 | [0, 4] | 0.50 |
| Disinhibitions | 9 (9) | 0 | [0, 0] | 15 (14) | 0 | [0, 1.5] | 0.16 |
| Irritability | 28 (27) | 0 | [0, 4] | 29 (28) | 0 | [0, 4] | 0.78 |
| Aberrant motor behaviour | 23 (22) | 0 | [0, 1] | 24 (23) | 0 | [0, 2.5] | 0.66 |
| Sleep disturbances | 25 (24) | 0 | [0, 3] | 28 (27) | 0 | [0, 4] | 0.82 |
| Appetite changes | 14 (13) | 0 | [0, 1] | 17 (16) | 0 | [0, 1] | 0.84 |
| Number of BPSD with symptom load of clinical relevance (NPI-12 domain score ≥4), range 0-12 | | 2 | [0, 4] | | 3 | [1, 5] | <0.001* |
| *Cornell Scale for Depression in Dementia (CSDD)* | | | | | | | |
| Total score, range 0-38 | 34 (33) | 5 | [3, 9] | 41 (39) | 7 | [4, 12] | 0.01* |

Table 3 legend:

Pre-pandemic: Six-month assessment of parent trial (12 Dec. 2019 to 11 Mar. 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). IQR: Interquartile range. P: P value for difference in median between time points by the Wilcoxon matched-pairs signed-rank test, * indicates two-tailed P <0.05. NPI-12 subsyndromes: psychosis (delusions and hallucinations), hyperactive behaviour (agitation, euphoria, irritation, disinhibition, aberrant motor behaviour), mood (depression, apathy, sleep disturbances, and appetite changes). #NPI domain scores ≥4 indicate BPSD with symptom load of clinical relevance. CSDD total score ≥8 indicates depression of clinical relevance

*Figure 2 here*

Table 4 shows the results of the logistic regression models exploring factors associated with worsening BPSD under the restrictions. Worsening NPI-12 total score was associated with postponed or averted contacts with health care professionals (OR 3.96, 95%CI 1.05 to 14.95) and impaired cognition as indicated by MMSE (OR 1.19, 95% CI 1.01 to 1.40), while a diagnosis of Alzheimer's disease relative to other dementia aetiologies was associated with lower OR of worsening NPI-12 (OR 0.18, 95%CI 0.05 to 0.63). Worsening psychosis subsyndrome score was associated with partial insight into the covid-19 situation (OR 9.57, 95%CI 1.14 to 80.71), reduced contact with the informal carer (OR 4.45, 95%CI 1.01 to 19.71), and impaired function as indicated by FAST (OR 2.59, 95%CI 1.07 to 6.27). An inverse association occurred for higher dependency in activities of daily living by PSMS and worsening psychosis subsyndrome (OR 0.68, 95%CI 0.51 to 0.91). Worsening depressive symptoms was associated with impaired function by FAST (OR 4.96, 95%CI 1.57 to 15.65), in contrast to lower odds associated with Alzheimer's disease (OR 0.21, 95%CI 0.05 to 0.85) and psychotropic drug use on-demand (OR 0.16, 95%CI 0.03 to 0.75).

Table 4: Factors associated with worsening in behavioural and psychological symptoms of dementia from the pre-pandemic to the pandemic assessment.

| | NPI-12 total score | | | | NPI-12 psychosis subsyndrome | | | | CSDD total score | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Covariates | OR | 95% CI lower | upper | P | OR | 95% CI lower | upper | P | OR | 95% CI lower | upper | P |
| *Pre-pandemic characteristics* | | | | | | | | | | | | |
| *Person with dementia* | | | | | | | | | | | | |
| Age | 1.01 | 0.92 | 1.11 | 0.79 | 0.91 | 0.82 | 1.01 | 0.16 | 1.09 | 0.97 | 1.22 | 0.16 |
| Female gender | 0.51 | 0.13 | 1.98 | 0.34 | 0.36 | 0.09 | 1.52 | 0.09 | 0.19 | 0.03 | 1.31 | 0.09 |
| Living alone | 0.20 | 0.04 | 1.01 | 0.05 | 2.69 | 0.41 | 17.80 | 0.31 | 0.55 | 0.07 | 4.18 | 0.57 |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Alzheimer's Disease[a] | 0.18 | 0.05 | 0.63 | 0.01* | 0.84 | 0.23 | 3.08 | 0.79 | 0.21 | 0.05 | 0.85 | 0.03* |
| MMSE[b] | 1.19 | 1.01 | 1.40 | 0.04* | 0.97 | 0.82 | 1.14 | 0.68 | 0.96 | 0.80 | 1.15 | 0.65 |
| FAST[c] | 0.98 | 0.45 | 2.16 | 0.97 | 2.59 | 1.07 | 6.27 | 0.04* | 4.96 | 1.57 | 15.65 | 0.01* |
| IADL[d] | 0.96 | 0.80 | 1.15 | 0.64 | 1.19 | 0.98 | 1.45 | 0.08 | 0.84 | 0.67 | 1.07 | 0.16 |
| PSMS[e] | 1.00 | 0.79 | 1.28 | 0.99 | 0.68 | 0.51 | 0.91 | 0.01* | 0.99 | 0.76 | 1.29 | 0.96 |
| GMHR[f] | 0.91 | 0.36 | 2.32 | 0.84 | 2.06 | 0.72 | 5.88 | 0.18 | 0.84 | 0.28 | 2.50 | 0.76 |
| Psychotropic drugs[g] | | | | | | | | | | | | |
| Regularly | 1.16 | 0.54 | 2.48 | 0.71 | 0.67 | 0.31 | 1.47 | 0.32 | 1.11 | 0.49 | 2.53 | 0.80 |
| On-demand | 0.35 | 0.09 | 1.46 | 0.15 | 2.95 | 0.69 | 12.66 | 0.15 | 0.16 | 0.03 | 0.75 | 0.02* |
| *Informal carer* | | | | | | | | | | | | |
| Age | 0.97 | 0.92 | 1.03 | 0.40 | 1.04 | 0.98 | 1.12 | 0.21 | 0.99 | 0.93 | 1.06 | 0.87 |
| Female gender | 1.81 | 0.50 | 6.49 | 0.36 | 0.70 | 0.18 | 2.80 | 0.62 | 0.82 | 0.16 | 4.27 | 0.82 |
| *Pandemic characteristics, person with dementia* | | | | | | | | | | | | |
| Insight to the covid-19 situation[h] | | | | | | | | | | | | |
| Partial | 0.61 | 0.10 | 3.69 | 0.60 | 9.57 | 1.14 | 80.71 | 0.04* | 0.67 | 0.10 | 4.44 | 0.68 |
| Sufficient | 1.14 | 0.15 | 8.82 | 0.90 | 3.69 | 0.33 | 40.93 | 0.29 | 2.70 | 0.26 | 28.27 | 0.41 |
| Contact with the informal carer[i] | | | | | | | | | | | | |
| Reduced | 1.88 | 0.48 | 7.44 | 0.37 | 4.45 | 1.01 | 19.71 | .049* | 1.40 | 0.27 | 7.27 | 0.69 |
| Increased | 2.41 | 0.61 | 9.49 | 0.21 | 3.21 | 0.71 | 14.55 | 0.13 | 0.30 | 0.07 | 1.23 | 0.10 |
| Ceased volunteering services | 0.30 | 0.04 | 2.24 | 0.24 | 0.20 | 0.02 | 2.11 | 0.18 | 0.59 | 0.04 | 7.91 | 0.69 |
| Change in health care services | 0.48 | 0.13 | 1.78 | 0.28 | 0.48 | 0.11 | 2.08 | 0.33 | 1.16 | 0.28 | 4.83 | 0.84 |
| Postponed or averted contacts with health care professionals | 3.96 | 1.05 | 14.95 | 0.04* | 1.55 | 0.45 | 5.42 | 0.49 | 3.37 | 0.70 | 16.08 | 0.13 |

Table legend:
n: 89 dyads (person with dementia and informal carer). Pre-pandemic: Six-month assessment of parent trial (12 Dec. 2019 to 11 Mar. 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). NPI-12: Neuropsychiatric Inventory, twelve item version; with psychosis subsyndrome constituting delusions and hallucinations (psychotic symptoms). CSDD: Cornell Scale of Depression in Dementia (depressive symptoms). Change dichotomised into worsening/not worsening. OR: Odds Ratio, explored by multiple logistic regression, estimates adjusted for all other factors in the models. 95%CI: 95% Confidence Interval. *P*: two-tailed, * indicates *P* value <0.05. [a]Alzheimer's disease, reference: all other dementia aetiologies. [b]MMSE, Mini-Mental Status Examination, at inclusion, range 0-30, higher scores indicate better cognition, reference: 30. [c] FAST, Functional Assessment Staging, at inclusion, range 1-7, lower scores indicate better functioning, reference: 1. [d]IADL, Instrumental Activities of Daily Living Scale, range 8-31, lower scores indicate better functioning, reference: 8. [e]PSMS, Physical Self-Maintenance Scale, range 6-30, lower scores indicate better functioning, reference 6. [f]GMHR, General Medical Health Rating Scale, range 1-4, lower score indicate higher comorbidity burden, reference 4. [g]Number of psychotropic drugs according to the Anatomical Therapeutic Chemical Index: antipsychotics (N05A), anxiolytics (N05B), hypnotics/sedatives (N05C), antidepressants (N06A), and anti-dementia drugs (N06D), reference: 0. [h]Degree of insight into the covid-19 situation as perceived by the informal carer, reference: no insight. [i]Change in contact with the informal carer, reference: no change.

Post-hoc analysis did not show any association between use of antipsychotic drugs before the restrictions and worsening psychosis subsyndrome using unequal variances t-test (supplementary table A). Similarly, we found no association between use of antidepressants and worsening depressive symptoms. Neither randomisation to the intervention vs. control of the parent trial showed associations with worsening NP-12 total score, psychosis subsyndrome nor depressive symptoms (supplementary table A). To explore if consecutive sampling introduced bias, we compared our study sample to those not included yet still in parent trial at the pre-pandemic assessment, revealing minimal differences (supplementary table B).

## DISCUSSION

Our primary aim was to compare pre- and pandemic levels of BPSD in home-dwelling people with dementia during the two first months of covid-19 restrictions in Norway. Even though BPSD fluctuates over the dementia course, our study indicates that the covid-19 restrictions caused an overall increase in BPSD over a mean of 86 days, and that odds of worsening were four times higher with postponed or averted contacts with health care professionals. More specifically, the increase was most pronounced for symptoms of psychosis and depression. The odds for worsening psychosis increased ten-fold with partial insight into the

covid-19 situation and four-fold with reduced contact with informal carers, while as-needed use of psychotropic drugs was associated with fewer depressive symptoms.

**Strengths and weaknesses**

Our study provides prospective data obtained shortly before and under the covid-19 restrictions rated by the same informal carer for each subject and based on extensive assessor-blinded interviews with validated, well-established instruments.[12, 13] We used established cut-off scores when presenting BPSD with symptom load of clinical relevance.[6, 19] The parent trial population was recruited from different municipalities to be representative to the Norwegian demographic in terms of dementia aetiology, severity, and symptomatology.[13] As our study sample was fairly similar to those dyads not included from the parent trial, we argue that our study was not biased by selection.

There are weaknesses to address. Despite efforts, we were not able to invite all potential respondents through consecutive sampling before the restrictions were eased for the first time, explaining the limited sample size. CSDD is not validated for telephone interviews [18] yet our findings using CSDD were consistent with the depression domain of NPI-12, which can be used as a telephone interview instrument.[16] Previous work has shown that carer psychosocial factors such as sense of competence, guilt, and relationship quality account for up to 56% of the variance in BPSD-related distress.[26] In the case of the pandemic, stress-related symptoms were experienced by two-thirds of family carers soon after the outbreak hit Italy (N=4,913) and were associated with incident or worsening BPSD.[9] The authors conclude that they could not determine whether increased BPSD were the cause or consequence of carer distress, as both counterparts were exposed to similar conditions during quarantine. Even though we did not assess such domains, these considerations apply to our study. Another point is that 28% of the informal carers reported reduced contact with the person with dementia, leaving them with less clinical observation. As 44% of the dyads were not living together, we suggest that some violated the restrictions to visit their loved ones and keep their obligations as careers, possibly mitigating the impact on BPSD. These weaknesses should be considered when interpreting the results, along with the wide confidence intervals of the covariates associated with worsening BPSD. Notably, our data capture the impact of the initial phase of the outbreak in Norway and can therefore not answer longer-term consequences from either reimposition or lengthening of invasive restrictions.

**Comparison with other studies**

This study provides data on the negative mental health consequences of the covid-19 restrictions for people with dementia. Using a nonrandomized, noncontrolled design to

evaluate causations may be reasonable in the pandemic scenario as no other way of assessing the impact of the covid-19 restrictions exist. However, our results should be interpreted with caution. The deterioration in BPSD could in theory be caused by the progression of the dementia syndrome itself, rather than being exacerbated by the pandemic restrictions. Arguing against this, change in BPSD over four months was substantially lesser in an observational cohort of nursing home residents of which the majority had dementia than what we demonstrate comparing pre-pandemic and pandemic symptom levels.[27]

Our findings echo a small body of the existing literature on this topic. A study from Spain noted increases in levels of agitation, apathy, and aberrant motor behaviour five weeks into lockdown in outpatients with mild cognitive impairment and Alzheimer's disease (N=40), but no increase in psychotic symptoms.[28] A cross-sectional study from Italy (N=139) describes exacerbation of psychotic symptoms in a small percentage of subjects with subjective cognitive decline, mild cognitive impairment, and dementia.[29] This study, in part, utilised self-assessments, that may have led to underreporting of delusions and hallucinations. Even though other studies are equivocal on whether psychosis worsened,[8, 9] UK registry data indicate higher antipsychotic prescription rates to people with dementia during the pandemic, and the authors speculate that this increase may be the result of worsened agitation and psychosis.[30] Meanwhile, our study revealed no associations between psychotropic drugs and psychosis, likely given that very few patients used antipsychotics before the pandemic, in addition to the lack of real-time prescription data throughout the outbreak. Because this is a nascent area of research, discrepancies may be attributed to heterogeneity in design, as well as dementia severity and aetiology.

Early findings suggest that older adults at group level are more resilient to the mental health effects of the pandemic than younger ones.[11] Nonetheless, our study adds to the cross-sectional reports calling attention to deteriorating depressive symptoms among people with dementia.[8-10] For better communication within and between dyads and their formal caregivers, digital devices may enhance individual support.[12] Further, anxiolytics and hypnotics/sedatives were associated with fewer depressive symptoms when used as-needed in our sample. These drugs are known to temporarily alleviate some of the symptoms assessed by the CSDD, such as anxiety, irritability and agitation. However, in line with national guidelines, we rather recommend that antidepressants are considered if severe symptoms persist.[31]

Our study supports the World Health Organisation's concerns that the pandemic would negatively impact the mental health of people with cognitive impairments.[5] Even though way of life varies globally, the policies implemented in response to covid-19 are likely equally

disruptive to the environment of home-dwelling people with dementia across nations.[3] We, therefore, argue that our findings are generalisable to other countries. Furthermore, they emphasise that nonpharmacological approaches still should be the first-line treatment to avoid BPSD deterioration regardless of context.

### Unanswered questions and future research

Future research should explore the long-term impact of the covid-19 restrictions on BPSD, and whether moderations or service innovations can mitigate worsening. Less than 5% of trials on covid-19 involve behavioural and mental health interventions,[32] emphasising the need for knowledge to adapt restrictions and navigate the unforeseeable consequences for persons with dementia and informal caregiver of the current, and future, pandemics.

## STATEMENTS

### Contributor and guarantor information

BSH was primary investigator. MHG, BSH, MV, and LIB designed and planned the study. MHG, MV, and LIB collected data. MHG did the data analysis, supervised by JM. MHG and LIB wrote the first draft of the manuscript. MHG, BSH, IVV, JM, MV, MN, and LIB were actively involved in interpreting the results, revising the manuscript, and approving the final version. LIB is responsible for the overall content as guarantor. The corresponding author attests that all listed authors meet the authorship criteria and that no others fulfilling authorship criteria are omitted.

### Acknowledgements

Renira Angeles (postdoctoral fellow, NORCE) and Nathalie Puaschitz (postdoctoral fellow, Western Norway University of Applied Sciences) contributed to data collection. Rune Samdal secured public and patient involvement. The motivation and willingness of dyads and municipal personnel in Bergen, Bærum, and Kristiansand made this study possible.

### Transparency statement

LIB (the manuscripts guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study; that no important aspects of the study have been omitted; and that any discrepancies from the study as originally planned (and, if relevant, registered).

### Funding statement

This work was supported by the Research Council of Norway (grant number 273581). The Norwegian Government and the G.C. Rieber Foundation supports the Centre for Elderly and Nursing Home Medicine, University of Bergen, organising the conduction of LIVE@Home.Path and PAN.DEM. The research was designed, conducted, analysed, interpreted, and written by the authors independently of the funding sources. All authors had

access to the data in the study and can take responsibility for the integrity of the data and the accuracy of data analysis.

**Competing interests declaration**

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: MHG, MV, JM, and LIB had financial support from the Research Council of Norway (grant number 273581), for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; IVV reports receiving honorarium as editor of the American Journal of Geriatric Psychiatry.

**Data sharing**

Relevant anonymised data are available at reasonable request. Data are fully available to collaborators and affiliated researchers.

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**Dissemination declaration**

The results of this study will be disseminated to relevant user organisations (Norwegian Health Organisation), participants, affiliated health care personnel and external healthcare workers, as well as health authorities.

**FIGURE LEGENDS**

**Figure 1: The parent trial, LIVE@Home.Path, including PAN.DEM.** The covid-19 restrictions replaced trial protocol from 12 Mar. until eased on 15 May 2020. None of the dyads (person with dementia and informal carer, n) received the intervention whilst the PAN.DEM interviews were conducted (20 Apr. to 15 May 2020). **Panel a: Timeline.** Vertical lines indicate assessments. The shaded parts illustrate the covid-19 restrictions, postponing the LIVE-Intervention (Learning, Innovation, Volunteers, and Empowerment) for the dyads of Group 2. **Panel b: Flowchart.** This study includes the dyads of PAN.DEM completing the

pre-pandemic assessment before the covid-19 restrictions was implemented on 12 Mar. 2020. *Parent trial attrition: rate within assumptions of loss to follow-up.

**Figure 2: Change in behavioural and psychological symptoms in n (%) persons with dementia from the pre-pandemic to the pandemic assessment.** n: 104. Pre-pandemic: Six-month assessment of parent trial (12 Dec. 2019 to 11 Mar. 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). Neuropsychiatric Inventory, subsyndrome score: psychosis (delusions and hallucinations), hyperactive behaviour (agitation, euphoria, irritation, disinhibition, aberrant motor behaviour), mood (depression, apathy, sleep disturbances, and appetite changes). Cornell Scale for Depression in Dementia, total score.

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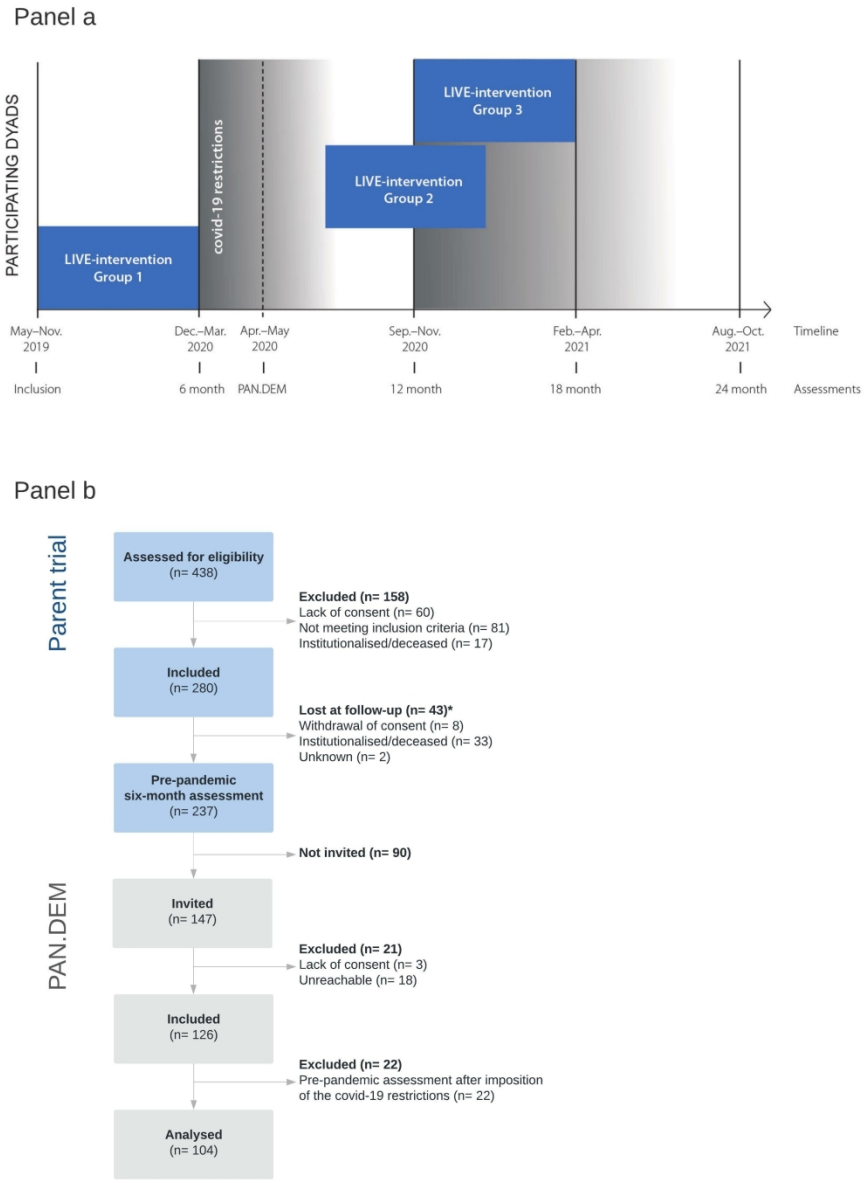


**Figure 1: The parent trial, LIVE@Home.Path, including PAN.DEM.** The covid-19 restrictions replaced trial protocol from 12 Mar. until eased on 15 May 2020. None of the dyads (person with dementia and informal carer, n) received the intervention whilst the PAN.DEM interviews were conducted (20 Apr. to 15 May 2020). **Panel a: Timeline.** Vertical lines indicate assessments. The shaded parts illustrate the covid-19 restrictions, postponing the LIVE-Intervention (Learning, Innovation, Volunteers, and Empowerment) for the dyads of Group 2. **Panel b: Flowchart.** This study includes the dyads of PAN.DEM completing the pre-pandemic assessment before the covid-19 restrictions was implemented on 12 Mar. 2020. *Parent trial attrition: rate within assumptions of loss to follow-up.

243x330mm (300 x 300 DPI)

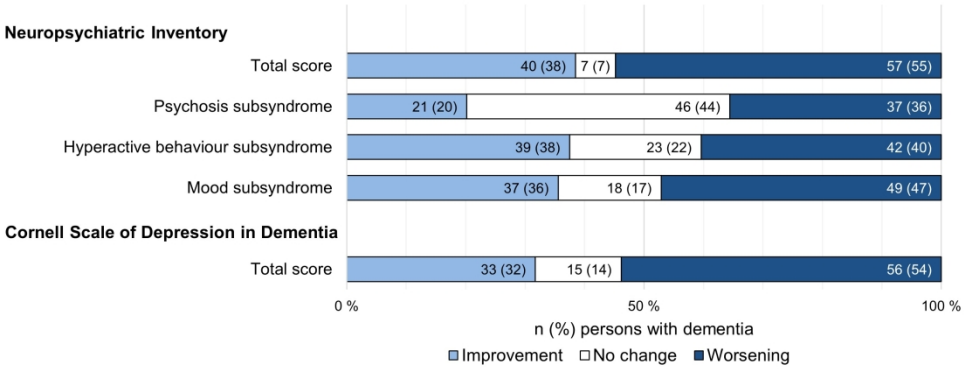


**Figure 2: Change in behavioural and psychological symptoms in n (%) persons with dementia from the pre-pandemic to the pandemic assessment.** n: 104. Pre-pandemic: Six-month assessment of parent trial (12 Dec. 2019 to 11 Mar. 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 2020). Neuropsychiatric Inventory, subsyndrome score: psychosis (delusions and hallucinations), hyperactive behaviour (agitation, euphoria, irritation, disinhibition, aberrant motor behaviour), mood (depression, apathy, sleep disturbances, and appetite changes). Cornell Scale for Depression in Dementia, total score.

223x86mm (330 x 330 DPI)

Supplementary table A: Post-hoc analysis of associations between worsening in behavioural and psychological symptoms (from the pre-pandemic to the pandemic assessment) and pre-pandemic traits for the 104 persons with dementia.

| | mean (SD) | P |
|---|---|---|
| NPI-12 total score | | |
| Use of psychotropic drugs (N05A, N05B, N05C, N06A, N06D) | | |
| Yes | 0.58 (0.50) | 0.36 |
| No | 0.47 (0.51) | |
| Use of antidementia drugs (N06D) | | |
| Yes | 0.58 (0.50) | 0.85 |
| No | 0.48 (0.50) | |
| Receiving the LIVE-intervention[#] | | |
| Yes | 0.57 (0.51) | 0.81 |
| No | 0.54 (0.40) | |
| NPI-12 psychosis subsyndrome | | |
| Use of antipsychotic drugs (N05A) | | |
| Yes | 0.33 (0.52) | 0.92 |
| No | 0.36 (0.48) | |
| Receiving the LIVE-intervention[#] | | |
| Yes | 0.29 (0.46) | 0.45 |
| No | 0.37 (0.49) | |
| CSDD total score | | |
| Use of antidepressant drugs (N06A) | | |
| Yes | 0.63 (0.50) | 0.88 |
| No | 0.61 (0.49) | |
| Receiving the LIVE-intervention[#] | | |
| Yes | 0.62 (0.50) | 0.97 |
| No | 0.61 (0.49) | |

Table legend:

Pre-pandemic: Six-month assessment of the parent trial (12 Dec 2019 to 11 Mar 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 15 2020). SD: standard deviation. P: P values for difference between groups by unequal variances t-test, * indicates two-tailed P<.05. NPI-12: Neuropsychiatric Inventory, twelve item version: with psychosis subsyndrome constituting delusions and hallucinations. CSDD: Cornell Scale of Depression in Dementia. Change dichotomised into worsening/not worsening. Drugs classified by the Anatomical Therapeutic Chemical Index. [#]21 (20%) received the LIVE-intervention: Multicomponent intervention of the parent trial comprising Learning, Innovation, Volunteers, and Empowerment.

Supplementary table B: Comparison of PAN.DEM study sample to those not included yet still in parent trial.

| | Pre-pandemic six-month assessment of parent trial (n=237) | | |
|---|---|---|---|
| | PAN.DEM study sample (n=104) | Not included in PAN.DEM study sample (n=133) | P |
| *Person with dementia* | | | |
| Age, mean (SD) | 82 (7) | 83 (7) | 0.38 |
| Female gender, n (%) | 63 (61) | 86 (65) | 0.47 |
| Residency | | | 0.93 |
| Living alone, n (%) | 46 (44) | 54 (41) | |
| Coresiding with the reporting informal carer, n (%) | 46 (44) | 59 (44) | |
| Coresiding with someone else than the informal carer, n (%) | 12 (12) | 16 (12) | |
| Dementia aetiology by ICD-10 | | | 0.003* |
| Alzheimer's Disease, n (%) | 45 (43) | 43 (32) | |
| Vascular Dementia, n (%) | 6 (6) | 2 (2) | |
| Dementia in other diseases classified elsewhere, n (%) | 10 (10) | 4 (3) | |
| Unspecified Dementia, n (%) | 43 (41) | 82 (62) | |
| MMSE, range 0-30, median [IQR] | 21 [18, 24] | 21 [18, 23] | 0.83 |
| FAST, range 1-7, median [IQR] | 4 [4, 4] | 4 [4, 5] | 0.15 |
| GMHR, range 1-4, median [IQR] | 3 [2, 3] | 3 [3, 4] | <0.001* |
| PSMS, range 6-30, median [IQR] | 11 [9, 14] | 11 [9, 14] | 0.40 |
| IADL, range 8-31, median [IQR] | 22 [18, 27] | 22 [16, 27] | 0.65 |
| Drugs in general, total number, median [IQR] | 6 [4, 8] | 4 [2, 7] | 0.002* |
| Psychotropic drugs | | | |
| Total number, median [IQR] | 1 [0, 1] | 1 [0, 2] | 0.02* |
| Regularly, median [IQR] | 1 [0, 1] | 1 [0, 1] | 0.07 |
| On-demand, median [IQR] | 0 [0, 0] | 0 [0, 0] | 0.06 |
| Health care services | | | |
| Daily Home Nursing, n (%) | 52 (50) | 46 (35) | 0.02* |
| Weekly Day Care, n (%) | 29 (28) | 37 (28) | 0.99 |

| | | | |
|---|---|---|---|
| Respite Care (In-Home and Out-of-Home), n (%) | 2 (2) | 9 (7) | 0.08 |
| Volunteering services, n (%) | 8 (8) | 22 (17) | 0.14 |
| *Behavioural and psychological symptoms of dementia* | | | |
| NPI-12 total score, range 0-144, median [IQR] | 16 [4.5, 29] | 12.5 [4, 28] | 0.74 |
| CSDD total score, range 0-38, median [IQR] | 5 [3, 9] | 6 [2, 12] | 0.32 |
| *Informal carer* | | | |
| Age, mean (SD) | 65 (12) | 68 (12) | 0.17 |
| Female gender, n (%) | 68 (65) | 83 (62) | 0.64 |
| Kinship to the person with dementia | | | 0.06 |
| Spouse, n (%) | 44 (42) | 58 (44) | |
| Child, n (%) | 58 (56) | 63 (47) | |
| Others, n (%) | 2 (2) | 12 (9) | |

Table legend:

n: dyads (person with dementia and informal carer). IQR: Interquartile range. SD: standard deviation. P: P values for difference between groups by two sample t-test, Wilcoxon-Mann-Whitney test, or Pearson chi-squared test, * indicates P<.05 ICD-10: International Statistical Classification of Diseases and Related Health Problems. MMSE: Mini-Mental Status Examination, at inclusion. FAST, Functional Assessment Staging, at inclusion. GMHR: General Medical Health Rating Scale. PSMS: Physical Self-Maintenance Scale. IADL: Instrumental Activities of Daily Living Scale. NPI-12: Neuropsychiatric Inventory. CSDD: Cornell Scale for Depression in Dementia. Drugs were classified by the Anatomical Therapeutic Chemical Index; antipsychotics, anxiolytics, hypnotics/sedatives, antidepressants, and anti-dementia drugs constituted psychotropic drugs.

# The PAN.DEM assessment

Respondents: informal carers in the LIVE@Home.Path trial

1 **Date of birth:** mm.dd.yyyy

2 **Are you temporarily laid off due to the covid-19 restrictions?**

- ☐ Yes
- ☐ No
- ☐ Not applicable

3 **During the last month, have you been quarantined due to covid-19?**

- ☐ Yes
- ☐ No

**If yes, please specify:**

_____

4 **Does the person with dementia have insight into the covid-19 situation?**

- ☐ To no degree
- ☐ Partial
- ☐ Sufficient

5 **To what degree are you concerned that the person with dementia will be infected with covid-19?**

Tick a number on the scale from 0-10 (0=not at all; 10=as much as possible):

0 1 2 3 4 5 6 7 8 9 10

6 **To what degree are you concerned that you yourself will be infected with covid-19?**

Tick a number on the scale from 0-10 (0=not at all; 10=as much as possible)

0 1 2 3 4 5 6 7 8 9 10

7 **To what degree are you concerned that you yourself will be infected with covid-19?**

Tick a number on the scale from 0-10: (0=not at all; 10=as much as possible):

0 1 2 3 4 5 6 7 8 9 10

8 **To what degree are your concern for own infection sourced from your responsibilities as carer?**

Tick a number on the scale from 0-10:(0=not at all; 10=as much as possible):

0 1 2 3 4 5 6 7 8 9 10

9 **As a response to the covid-19 pandemic, did you discuss advanced care planning with the person with dementia?** If yes, please specify below.

_____

10 **Did the covid-19 restrictions have any consequences for the healthcare services provided by the municipality for the person with dementia** (e.g. home nursing services, activity groups, day care centre, respite care).

☐ Yes
☐ No

**If yes, specify per Resource Utilization in Dementia Version 4 section A2.2.5** [1 2]

11 **Have you avoided or postponed contacts with health care professionals due to the COVID-19 pandemic and the restrictions?**

☐ Yes
☐ No

**If yes, please specify:**

_____

12 **Informal care time assessed by Resource Utilization in Dementia Version 4 section B1.2** [1 2]

13 **Has the food habits and appetite of the person with dementia changed under to the covid-19 restrictions?**

☐ Yes
☐ No

**If yes, please specify:** Tick one or several items.

☐ Eats/drinks less
☐ Loss of appetite
☐ Eats more
☐ Eats mote unhealthy food
☐ Has stopped preparing food him/herself
☐ Heats prepared food
☐ Is unable to maintain diet without help from informal or formal carers

14 **Neuropsychiatric inventory (12 item version)** [3]

15 **Cornell Scale of Depression in Dementia** [4]

16 **Has the pandemic had any consequences for services provided by volunteers?**

☐ Yes
☐ No

**If yes, specify as applicable:**

_____

17 **Has the covid-19 restrictions increased your interest in assistive technology?**

☐ Yes
☐ No

**If yes, specify as applicable** including complaint/need, type of technology, if acquired, including privately financed or municipally funded:

_____

18 **Compared to pre-pandemic levels, what sort of contact have you had with the person with dementia?** Tick one or several items.

- ☐ Unchanged
- ☐ Increased
- ☐ Reduced
- ☐ No contact at all
- ☐ More digital contact

19 **Have you implemented measures and restrictions to prevent transmission of covid-19 to the person with dementia?** Please specify as applicable:

_____

20 **Compared to immediately before the pandemic, how would you rank your own total situation as a carer?** [5]

Tick a number from -5 (much worse) to 5 (much better), via 0 (no change).

-5 -4 -3 -2 -1 0 1 2 3 4 5

21 **Do you have any additional comments?** Please specify as applicable:

_____



## References


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STROBE Statement—checklist of items that should be included in reports of observational studies

| | Item No | Recommendation | Page in manuscript |
|---|---|---|---|
| **Title and abstract** | 1 | (*a*) Indicate the study's design with a commonly used term in the title or the abstract | Page 1 and 2 |
| | | (*b*) Provide in the abstract an informative and balanced summary of what was done and what was found | Page 2 |
| **Introduction** | | | |
| Background/rationale | 2 | Explain the scientific background and rationale for the investigation being reported | Page 3 and 4 |
| Objectives | 3 | State specific objectives, including any prespecified hypotheses | Page 4 |
| **Methods** | | | |
| Study design | 4 | Present key elements of study design early in the paper | Page 4 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | Page 4 |
| Participants | 6 | (*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up<br>*Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls<br>*Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants | Page 4 and figure 1 |
| | | (*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed<br>*Case-control study*—For matched studies, give matching criteria and the number of controls per case | Not applicable |
| Variables | 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | Page 5 |
| Data sources/ measurement | 8* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | Page 5 |
| Bias | 9 | Describe any efforts to address potential sources of bias | Page 4 |
| Study size | 10 | Explain how the study size was arrived at | Page 6 |
| Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why | Page 6 |
| Statistical methods | 12 | (*a*) Describe all statistical methods, including those used to control for confounding | Page 6 |
| | | (*b*) Describe any methods used to examine subgroups and interactions | Page 6 and 13 |
| | | (*c*) Explain how missing data were addressed | Page 6 |

| | | | |
|---|---|---|---|
| | | (*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed<br>*Case-control study*—If applicable, explain how matching of cases and controls was addressed<br>*Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy | Figure 1, page 13 |
| | | (*e*) Describe any sensitivity analyses | Page 13 |
| **Results** | | | |
| Participants | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed | Page 7 and figure 1 |
| | | (b) Give reasons for non-participation at each stage | Figure 1 |
| | | (c) Consider use of a flow diagram | Figure 1 |
| Descriptive data | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders | Page 7, table 1, table 2 |
| | | (b) Indicate number of participants with missing data for each variable of interest | Page 6 |
| | | (c) *Cohort study*—Summarise follow-up time (eg, average and total amount) | Page 7 |
| Outcome data | 15* | *Cohort study*—Report numbers of outcome events or summary measures over time | Page 9, table 3 |
| | | *Case-control study*—Report numbers in each exposure category, or summary measures of exposure | |
| | | *Cross-sectional study*—Report numbers of outcome events or summary measures | |
| Main results | 16 | (*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | Page 6 and 11, table 3 and table 4 |
| | | (*b*) Report category boundaries when continuous variables were categorized | Page 6 and table 4 |
| | | (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | Not applicable |
| Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses | Page 13 |
| **Discussion** | | | |
| Key results | 18 | Summarise key results with reference to study objectives | Page 13 |
| Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | Page 14 |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | Page 13-16 |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results | Page 14 and 16 |
| **Other information** | | | |
| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | Page 16 |

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.